

EXPLORING STRATEGIES TO IMPROVE
**CARDIAC ARREST
SURVIVAL**

Proceedings of a Workshop

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Board on Population Health and Public Health Practice

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**PLANNING COMMITTEE ON A DISSEMINATION
WORKSHOP ON THE STRATEGIES TO IMPROVE
CARDIAC ARREST SURVIVAL REPORT¹**

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¹ The National Academies of Sciences, Engineering, and Medicine’s planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published Proceedings of a Workshop rests with the workshop rapporteurs and the institution.

Reviewers

This Proceedings of a Workshop has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published Proceedings of a Workshop as sound as possible and to ensure that the Proceedings of a Workshop meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this Proceedings of a Workshop:

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Clyde Yancy, Northwestern University

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the Proceedings of a Workshop before its release. The review of this Proceedings of a Workshop was overseen by **Dan G. Blazer**, Duke University Medical Center. He was responsible for making certain that an independent examination of this Proceedings of a Workshop was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this Proceedings of a Workshop rests entirely with the rapporteurs and the institution.

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Introduction¹

Cardiac arrest often strikes seemingly healthy individuals without warning and without regard to age, gender, race, or health status. Representing the third leading cause of death in the United States, cardiac arrest is defined as “a severe malfunction or cessation of the electrical and mechanical activity of the heart . . . [which] results in almost instantaneous loss of consciousness and collapse” (IOM, 2015, p. 1). Although the exact number of cardiac arrests is unknown, conservative estimates suggest that approximately 600,000 individuals experience a cardiac arrest in the United States each year (Daya et al., 2015; IOM, 2015; Merchant et al., 2011).² Of these, approximately 12,500 are children (Atkins et al., 2009; Morrison et al., 2013). Cardiac arrest survival rates are persistently low; for example, fewer than 6 percent of people who experience out-of-hospital cardiac arrests (OHCAs) survive (Daya et al., 2015; IOM, 2015).

Cardiac arrest survival rates vary widely among communities and

¹ The planning committee’s role was limited to planning the workshop, and the workshop proceedings was prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, and have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine; they should not be construed as reflecting any group consensus.

² This number includes approximately 395,000 people who have cardiac arrests outside the hospital (i.e., out-of-hospital cardiac arrests [OHCAs]) and 200,000 cardiac arrests occurring in hospitals (i.e., in-hospital cardiac arrests [IHCA]).

hospitals and may be influenced by “individual demographics (e.g., race, age, gender, health status), location of arrest, initial cardiac arrest rhythm, rates of bystander cardiopulmonary resuscitation (CPR) and automated external defibrillator (AED) use, and characteristics of emergency medical services (EMS) and health care systems (e.g., response time, treatment availability, training, and care quality)” (IOM, 2015, p. 2). Moreover, negative outcomes from cardiac arrest disproportionately affect populations that are already at risk for poor health status (IOM, 2015). Yet some benchmark communities have demonstrated greater than 60 percent survival rates for specific types of witnessed OHCAs and have significantly increased rates of good neurologic and functional outcomes (see, e.g., Chatalas and Plorde, 2014), providing examples of what can be accomplished through organized and sustained actions of individuals and within systems of care.

On June 30, 2015, the Institute of Medicine (IOM)³ released its consensus report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*, which evaluated the factors affecting resuscitation research and outcomes in the United States. Focusing on the public health dimensions of cardiac arrest treatment, the report included eight recommendations (see Appendix A) that emphasized the following:

1. Establishing a national cardiac arrest registry
2. Fostering a culture of action through public awareness and training
3. Enhancing the capabilities and performance of EMS systems
4. Setting national accreditation standards related to cardiac arrest for hospitals and health care systems
5. Adopting continuous quality improvement programs
6. Accelerating research on pathophysiology, new therapies, and translation of science for cardiac arrest
7. Accelerating research on the evaluation and adoption of cardiac arrest therapies
8. Creating a national cardiac arrest collaborative

Following the release of the consensus report, eight sponsors asked the Health and Medicine Division (HMD) to hold a 2-day workshop to assemble diverse stakeholders who would explore the barriers and opportunities for advancing the IOM recommendations (see Box 1-1). The

³ As of March 15, 2016, the Health and Medicine Division continues the consensus studies and convening activities previously undertaken by the IOM. Publications released prior to this change should be cited to the IOM in perpetuity, but all subsequent publications are branded under the National Academies of Sciences, Engineering, and Medicine.

BOX 1-1
Health and Medicine Division Dissemination
Workshop on the Strategies to Improve Cardiac
Arrest Survival Report: Task and Sponsors

Statement of Task

An ad hoc committee will organize a 2-day public workshop on short- and long-term strategies to respond to the recent Institute of Medicine (IOM) report *Strategies to Improve Cardiac Arrest Survival: A Time to Act* (IOM, 2015).

The workshop will bring together diverse stakeholders to explore common ground and different approaches to advance the field of resuscitation and the treatment of cardiac arrest, building on recommendations included in the IOM report. The workshop will feature presentations and discussions on the following topics:

- Encouraging data collection and dissemination
- Promoting public education and training
- Improving delivery of high-quality resuscitation and postarrest care
- Enhancing the impact of cardiac arrest research and therapies
- Strengthening stakeholder collaboration

The committee will develop the agenda topics, select and invite speakers and discussants, and moderate the discussions. A summary of the workshop's presentations and discussions will be prepared by a designated rapporteur in accordance with institutional guidelines.

Sponsors

Sponsors are the American Heart Association; American Red Cross; Asmund S. Laerdal Foundation; Centers for Disease Control and Prevention; Medtronic Foundation; Physio-Control, Inc.; Sudden Cardiac Arrest Foundation; and ZOLL Medical Corporation.

workshop was held on July 11 and 12, 2016, with more than 120 in-person participants and 80 participants via webcast. The workshop agenda (see Appendix B) included five plenary sessions with panel presentations that focused on the IOM's individual recommendations. Following each panel, members of the planning committee and the audience were able to make comments and pose questions to the speakers. Each plenary session was followed by one or more breakout groups, in which participants were asked to respond to a predetermined set of questions. Planning committee members moderated these breakout groups and presented summaries of the group discussions during the plenary session.

Generally, the format of this summary follows the structure of the workshop. However, some of the content has been rearranged to better highlight themes that emerged throughout the workshop and to enhance the flow of the material presented. The workshop rapporteurs have prepared this summary as a factual summation of the workshop discussions. The views included in this summary are solely the views of the workshop speakers and participants and do not represent the views of the National Academies of Sciences, Engineering, and Medicine; the planning committee; or other speakers and workshop participants, as a whole. Text that appears under individual presentations is wholly attributable to the presenter, unless stated otherwise.

This chapter provides background information on the origin of the dissemination workshop, offers perspectives from cardiac arrest survivors, and summarizes the overarching themes that emerged from workshop presentations and discussions. Chapter 2 discusses opportunities to advance cardiac arrest surveillance. Chapter 3 considers barriers and opportunities to advance research and the translation of research into care settings. Chapter 4 addresses issues related to public awareness and training. Chapters 5 and 6 focus on possible strategies to improve the quality of EMS and hospital system response to cardiac arrest, respectively. Finally, Chapter 7 examines the discussion regarding partnerships and the development of a cardiac arrest collaborative.

IMPROVING THE CHAIN OF SURVIVAL

Tom Aufderheide, Planning Committee Chair

Tom Aufderheide, planning committee chair, opened the meeting by thanking sponsors, participants, HMD staff, and the planning committee and providing a brief overview of highlights from the IOM report. He emphasized that the number of productive life years lost due to death and disability attributable to cardiac arrest signifies an enormous public health burden. Although there are effective and evidence-based actions and treatments that can significantly reduce death and disability from cardiac arrest, there are disparities in the access to, and application of, these treatments (IOM, 2015). As characterized by the chain of survival (see Figure 1-1), critical steps include early access to care through emergency 911 services, bystander-administered CPR, early defibrillation, high-performance EMS resuscitation practices, and optimized hospital-based care following a cardiac arrest. If these treatment options were more efficiently and comprehensively implemented, rates of death and disability could be reduced across the United States, said Aufderheide.

Although the chain of survival is useful for guiding actions at the

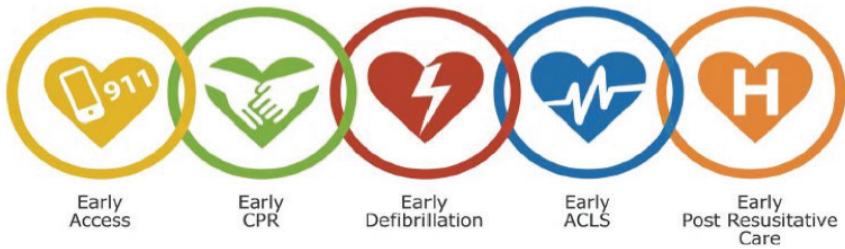


FIGURE 1-1 Cardiac arrest chain of survival.

NOTE: ACLS = advanced cardiac life support; CPR = cardiopulmonary resuscitation.

SOURCE: Presented by Tom Aufderheide, July 11, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act* (citing Resuscitation Academy, n.d., p. 14).

operational level, the IOM report suggested that a more unifying, overarching framework for the resuscitation field was needed, explained Aufderheide. Taken as a whole, the new framework (see Figure 1-2) was meant to identify relationships and coordinate action. It includes the primary goal—improving survival and patient outcomes—as the roof of the structure, said Aufderheide. The foundation and steps represent a comprehensive, integral, and system-wide response that is required to rejuvenate the resuscitation field and improve public health (IOM, 2015). These steps provide a strong foundation for the five stakeholder groups, which are directly and indirectly responsible for the effective response to cardiac arrest and, ultimately, patient outcomes. Leadership, combined with accountability and transparency, are cornerstones for the entire framework.

Aufderheide emphasized the need to transform a culture of inaction into a culture of collaborative action. He remarked that this need for culture change spans the field and is applicable to all stakeholder groups—the public, EMS agencies, hospitals, health care providers, researchers, policy makers, and the full range of organizations and government agencies that are linked to resuscitation and cardiac arrest. Arthur Kellermann, one of the presenters, supported Aufderheide’s assertion, stating that the limited progress in cardiac arrest outcomes and of the resuscitation field, more broadly, are not a failure of knowledge, but rather a failure of action.

Aufderheide concluded by explaining that workshop presenters included a number of cardiac arrest experts, as well as speakers from outside the cardiac arrest community, whose experiences could serve as

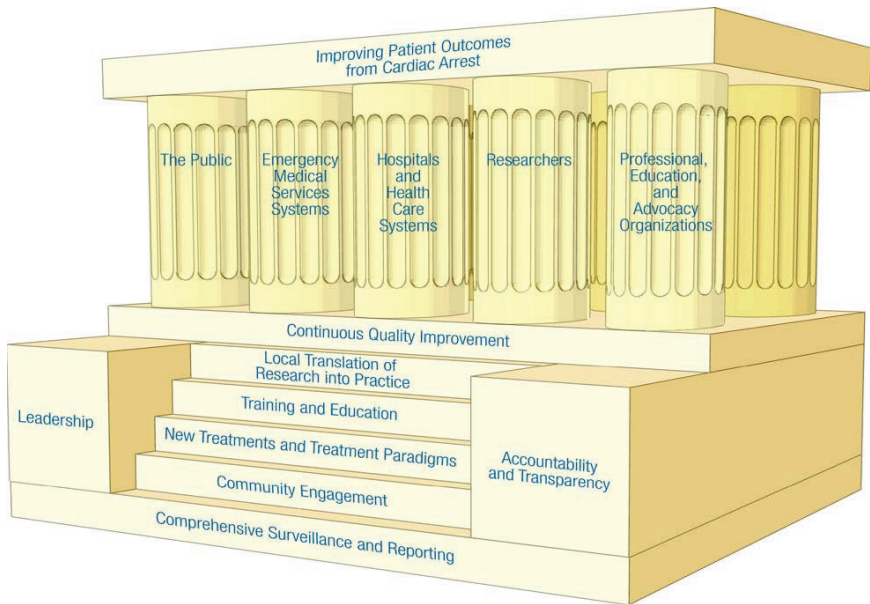


FIGURE 1-2 A unifying framework for improving patient outcomes from cardiac arrest.

SOURCE: Presented by Tom Aufderheide, July 11, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act* (citing IOM, 2015, p. 7).

valuable examples to be interpreted and applied in the context of resuscitation. He urged participants to use the workshop to form new alliances and collaborations and to establish an action plan from which to advance the IOM report recommendations and improve cardiac arrest survival throughout the United States.

SURVIVING CARDIAC ARREST: THE REASON FOR ACTION

During the workshop, three speakers shared their personal cardiac arrest survival stories. The Sudden Cardiac Arrest Foundation also debuted a short video that featured survivors and their families, emphasizing the impact of immediate public reaction to cardiac arrest and urging members of the public to pursue CPR and AED training. These speakers offered perspectives on how the IOM report recommendations could be advanced and how survivors, the community, and the public could be involved in shaping the agenda moving forward. As Aufderheide noted, survivors represent a network of individuals whose lives have

been altered by cardiac arrest—spouses, children, parents, friends, and co-workers. Successful resuscitation and improved cardiac arrest outcomes affect not only the survivor but also the constellation of individuals who are closely connected to the survivor. Aufderheide said these stories of survival and the lives of the people touched by cardiac arrest are catalyzing action.

The Driving Force Behind Needed Change

James Niskanen, Sudden Cardiac Arrest Survivor

“It’s a great day to be alive! . . . I certainly have a renewed sense of what a great day of being alive means,” said James Niskanen, who had survived cardiac arrest 8 years prior to the workshop. Niskanen spoke to the audience not only as a survivor, but also as a *thrivor*—someone who has moved beyond the initial survival of cardiac arrest and has gone on to experience a successful, fulfilling life.

Niskanen was teaching at a seminar in 2008 when he began to feel awkward, but initially dismissed the feelings as inconsequential. However, soon Niskanen began to sweat profusely and started feeling light-headed, eventually passing out and hitting his head on the podium as he fell to the ground. As described by his best friend, Niskanen experienced “a perfect storm of good fortune” that day, because he was in a room full of CPR-trained individuals. Two women from the audience initiated CPR and others ran to retrieve a nearby defibrillator. A group of people formed a line to meet and direct the first responders. He was revived quickly with awareness of his surroundings, asking a colleague to finish his presentation for him as he was being taken to the ambulance. At the hospital, Niskanen was greeted with a capable response team. Following postarrest care, Niskanen was able to return home, where he continues to receive follow-up care in California.

Shortly after his cardiac arrest, Niskanen retired and became involved with the Citizen CPR Foundation and began speaking to interested stakeholders, including researchers, health care providers, and local communities. He was able to celebrate his 40th wedding anniversary and enjoys spending time with his grandchildren, some of whom had not yet been born prior to his cardiac arrest.

Unfortunately, not everyone survives and thrives following a cardiac arrest, said Niskanen. Just a week and a half before the HMD workshop, Niskanen lost a close friend to cardiac arrest. Despite best efforts, there were multiple breakdowns along the chain of survival; the preliminary CPR response was not optimal and the bystanders did not know where to find available AEDs. Although strengthening links in the chain of survival

may not have saved his friend, said Niskanen, it would have given him a better chance to survive.

Survivor Perspective

Kelly Sawyer, Sudden Cardiac Arrest Survivor

At the time of her cardiac arrest, Kelly Sawyer was completing a medical fellowship in emergency cardiac care and resuscitation at Virginia Commonwealth University. Near the end of her fellowship, she collapsed on campus. Two people witnessed her arrest and called 911 because the hospital code team did not respond promptly. Upon arrival the EMS personnel resuscitated Sawyer and transported her to the emergency department. Her colleagues were able to call on cardiologists, cardiac surgeons, and other specialists in a facility where access to advanced lifesaving techniques, such as extracorporeal membrane oxygenation (commonly known as ECMO) were available.

During the preliminary postarrest assessment, the emergency care physicians identified the underlying cause of Sawyer's arrest—a massive pulmonary embolism. Sawyer was taken into emergency surgery, which was followed by the use of therapeutic hypothermia—her own area of research. Fortunately for Sawyer, everything was aligned in her favor—from the day of the week and the time of the day that the arrest occurred to the presence of a comprehensive postarrest care system. These factors and the available resources ensured not only her survival but also her quality of life. Sawyer emphasized the need for hospitals and medical systems to have effective response plans for cardiac arrests that occur on campus and beyond the reach of in-house response teams. From Sawyer's perspective, postresuscitation care on how to ensure the functionality of patients who do survive was paramount.

From Expert to Survivor

Joseph Ornato, Virginia Commonwealth University

Joseph Ornato began by stating that, unlike other meetings on resuscitation, he had not been invited to speak as a lifelong researcher on the prevention and treatment of sudden cardiac arrest. Instead he had been asked to talk about being the beneficiary of his colleagues' actions and knowledge, both in the EMS and hospital systems, when he suffered a massive pulmonary embolus a little more than 1 year ago. As a fairly well informed consumer in resuscitation, Ornato underscored the importance of translating the IOM report into action, including improving EMS and

hospital system performance to reflect existing knowledge. He emphasized the role of communities to implement what is already known to improve cardiac arrest survival. “It really does take a village to save a life from sudden cardiac arrest. The enemy of this particular problem is time . . . we can’t biologically control time, but we can stretch it [using techniques] such as citizen bystander CPR,” said Ornato. Improvements must occur at a local level, but it will require collaboration to bridge what have been siloed activities. Examples of success from other fields, such as the National Breast Cancer Coalition, can give us a vision and concrete guidance on how to advance our work together, concluded Ornato.

WORKSHOP THEMES

Throughout the workshop, panelists, planning committee members, and participants exchanged ideas, shared diverse perspectives, and considered the path forward for improving cardiac arrest response and outcomes. As the participants discussed opportunities and challenges connected to implement recommendations from the IOM report, a number of themes emerged from the presentations and discussions (see Box 1-2). These themes should not be viewed as conclusions or recommendations from the National Academies of Sciences, Engineering, and Medicine. Furthermore, these themes should not be interpreted as a consensus of the planning committee, speakers, or workshop participants cumulatively.

Investing in Survivors and Families

A number of workshop participants underscored the need to include more survivors and families in all resuscitation partnerships, priority-setting activities, advocacy and education efforts, and other initiatives from the local level through the national level. Aufderheide, Robert Davis, Joanne Howes, Edward Septimus, among others, emphasized the value and perspective that survivors can and should bring to partnerships across all aspects of cardiac arrest initiatives. Septimus stated that these patients and families can provide indispensable passion, advocacy, and powerful personal stories to motivate change across the resuscitation field.

A few workshop participants expressed support for establishing a national survivor network that actively involves survivors, patient advocates, families, and individuals who have lost a loved one to cardiac arrest. Although cardiac arrest survivor organizations do exist, some members of two breakout sessions called for uniting the survivor and family organizations to create a more visible and active national survivor network with stronger leadership. This network could participate in policy decisions

BOX 1-2
Strategies to Improve Cardiac Arrest Survival:
Workshop Themes

Investing in Survivors and Families. Survivors and families are valuable to the resuscitation community and are central to all partnerships, priority-setting activities, advocacy and education efforts, and other initiatives from the local level through the national level.

Partnering to Expand Resources and Infrastructure. Given current resource limitations and the policy landscape, it is important to leverage existing resources and infrastructure and implement sustainable funding models and partnerships to effectively expand cardiac arrest surveillance and research activities.

Harmonizing Data and Research to Improve Performance. Improved data collection strategies; development of shared definitions, standards, and measures; and the availability of harmonized, interoperable data can enhance and expand surveillance, research and translation, and performance and quality improvement initiatives across health care settings.

Unifying Messaging and Broadening Engagement. Clear, consistent messaging and communication strategies can raise awareness of cardiac arrest as a serious public health concern and strengthen advocacy efforts. Traditional public awareness activities can complement strategies to engage different stakeholders and communities in various actions, including cardiopulmonary resuscitation and automated external defibrillator training and broader initiatives.

Cultivating Partnerships and Leadership. Although the diverse range of organizations and stakeholders across the resuscitation field has provided a wealth of experience and knowledge, stronger partnerships and collaborative leadership can further advance the field and improve cardiac arrest outcomes in the United States.

SOURCE: The workshop themes were identified by the workshop rapporteurs.

and be involved in efforts to educate the public about bystander CPR and AED use. To increase efficacy of the network and advocacy efforts, Howes remarked that participating survivors and family members should receive advocacy training and be centrally involved in outreach initiatives whenever possible.

Natasha Bonhomme and Gary Gibbons also emphasized the importance of patient, family, and public involvement throughout the research process. Bonhomme described the importance of building trust with patients and families to expand participation and involvement in the research process. She stated that participants should believe they are

playing an active role in research, not just a one-sided interaction in which they supply data to researchers. A number of workshop participants encouraged researchers and the resuscitation field to engage survivors and their families in a full range of activities, from setting research agendas and developing research questions to disseminating research findings and advocating for additional research funding. Niskanen commended community engagement at the neighborhood level, but noted that engagement can be difficult because it requires steadfast commitment, and some individuals or communities may be less receptive or do not share the same level of enthusiasm. Similarly, Davis emphasized the importance of enhanced public awareness to hold individuals accountable for a system's performance level and to instill a culture of action.

Partnering to Expand Resources and Infrastructure

Current resource limitations and the health policy landscape present ongoing challenges for cardiac arrest surveillance and research activities that may require leveraging existing resources and infrastructure and expanding sustainable funding models, noted a number of participants. Michael Frankel, Gibbons, and Robert Merritt described current funding restrictions and competing priorities across government agencies and health care systems. These challenges limit new or expanded funding opportunities for cardiac arrest surveillance, research, and education initiatives as a sole programmatic focus. Aufderheide and some other workshop participants argued that financial sustainability and accountability should be considered for all surveillance, research, and quality improvement initiatives. Aufderheide, Laura Langmade, Merritt, and others suggested fostering public-private partnerships to build sustainable funding mechanisms and expand cardiac arrest surveillance and research infrastructure.

Demetris Yannopoulos and some members of a breakout session suggested exploring a bundled funding mechanism or a national funding initiative (which could pool resources from large corporate foundations and national entities, such as the American Heart Association, the Department of Defense [DoD], the National Institutes of Health [NIH], the National Science Foundation, and the Patient-Centered Outcomes Research Institute) to allocate sustainable research funds for agreed-upon research goals. Jeremy Brown and some members of his breakout group identified a number of existing federal government research programs where cardiac arrest could build on existing funding, resources, infrastructure, and partnerships.

A number of speakers emphasized the value and possible benefits of building on previous successes (e.g., Cardiac Arrest Registry to Enhance

Survival [CARES], National Emergency Medical Services Information System [NEMSIS]) and partnering with other fields that have existing, and possibly overlapping, infrastructure (e.g., stroke, trauma, other cardiovascular diseases). Noah Smith challenged the field to rethink data collection in light of new initiatives and focus on creative approaches to extract cardiac arrest data from existing data infrastructures. Langmade also emphasized the role that cognitive computing can have in aggregating data from disparate sources to improve the delivery of health care services through the promise of big data and evolving data analytics. Langmade encouraged the field to consider how relevant data are generated and collected, how those data will be mapped and moved across systems, and how the data will be monitored and validated.

A number of speakers described parameters for enhancing existing data collection and infrastructure to expand knowledge and create new research opportunities. For example, Nigel Hughes called for a large-scale data source that could be used to follow patients over decades in order to learn more about long-term outcomes. Yannopoulos and several participants in his breakout session identified a number of alternative research methods that could be used to respond to methodological limitations (e.g., adaptive trials, stratified patient groups, individualized protocols). Additionally, Frankel described the need for a system that could collect data across the continuum of care, from before and after hospitalization and beyond. Septimus commented on the importance of developing tools and resources that are scalable and manageable for all health care systems, regardless of size or budget.

Harmonizing Data and Research to Improve Performance

Improving cardiac arrest outcomes will require enhanced data and harmonization to better characterize the epidemiology of cardiac arrest and measure the impact of strategies on system performance and patient outcomes, suggested participants such as Christine Albert and Aufderheide. Several panelists and participants commented on the need for standardized performance and outcome measures. Bonhomme suggested starting with a shared infrastructure for collecting common data points across multiple conditions, and then tailoring and expanding the platform, as needed, to collect data points that are unique to cardiac arrest. Merritt, Smith, and several workshop participants articulated the significance of harmonized data sources and interoperable data exchange systems. Additionally, Raina Merchant challenged the resuscitation field to find meaningful ways to harness data that are available through social media and crowdsourcing for research. Aufderheide, Gibbons, and a few individuals during breakout sessions encouraged greater focus on imple-

mentation science to improve the translation of basic clinical science into effective interventions.

A number of participants emphasized the essential role of performance measurement and continuous quality improvement to ultimately improve patient outcomes. Aufderheide highlighted the need to understand the causes of variability in cardiac arrest care and survival rates across the United States. Kellermann urged all communities to benchmark performance around a few measures associated with the chain of survival, especially in the context of prehospital care. A number of workshop participants suggested that the implementation of continuous quality improvement programs in hospitals and EMS systems could help reduce this variability. Peter Taillac noted that a focus on quality and performance improvement would also instill a culture of excellence.

Combined with quality improvement initiatives, some workshop participants suggested that regionalization could also present opportunities to reduce variations in patient outcomes and improve the performances of local EMS and hospital systems. For example, Drew Dawson stated that a regionalized system for dispatcher-assisted CPR would maximize available resources, ensure high-quality CPR instruction for every 911 caller, and support high levels of performance. Similar to regional stroke and trauma centers, Mark Alberts described how a national network of cardiac arrest centers could lead to improved quality of cardiac arrest care and better outcomes.

Vinay Nadkarni called for hospital performance measures that could easily be adapted, measured, and compared across populations from adults through neonates. Mimi Peberdy suggested mandating hospital reporting and developing specific interim performance and outcome measures along the entire sequence of resuscitation events rather than solely focusing on the final outcome—neurologically intact survival to hospital discharge. A few individuals during breakout sessions warned against onerous data collection and reporting systems in the absence of demonstrable impacts on outcomes. Septimus reiterated that all process measures must be linked to better outcomes, and unintended consequences need to be considered when developing and implementing new process measures. Additionally, a number of workshop participants described limitations of current coding systems, stating that the lack of separate codes for in-hospital cardiac arrests, OHcAs, and pediatric cardiac arrests, as well as the lack of available coding for specific cardiac arrest therapies, create significant research challenges.

A number of workshop participants noted the potential to align efforts among related fields to improve surveillance and research. Smith suggested that the resuscitation field faces many challenges related to surveillance and research that are not unique to cardiac arrest, registries,

EMS, or hospital care, in general. Taillac suggested that improvements to EMS systems' performance that combined cardiac arrest, trauma, stroke, and other fields could positively reshape patient safety and outcomes. Gibbons described the National Heart, Lung, and Blood Institute's new Precision Medicine Initiative Cohort Program, which aims to improve knowledge about myriad diseases by enhancing data collection and sharing on genetic, social environment, economic status, geography, among other factors, from a cohort of more than 1 million participants.

Unifying Messaging and Broadening Engagement

Unified messaging and communication strategies can elevate the visibility of cardiac arrest as a serious public health concern, educate the public, strengthen advocacy efforts, and build momentum for future progress and policies. Niskanen and other participants noted common confusion about the differences between heart attacks and cardiac arrest. Generally the public is familiar with the term *massive heart attack*, Niskanen noted, because it implies that nothing could have been done to save a person. Bystanders need to understand that cardiac arrest is not a heart attack and know how to recognize the former because an individual's actions can save a life, a number of workshop participants echoed.

A number of workshop participants observed that the lack of consistent messaging across the resuscitation field has hindered efforts to successfully engage communities and educate the public about cardiac arrest and the importance of bystander CPR. To overcome this barrier, Howes urged the field to come together and develop agreed-upon messaging and communication strategies to move the field forward with one voice. Davis, Howes, and Paul Pepe asserted that the messages need to be singular, simple, concise, easy to communicate, and compelling. To be effective, they said, the messages must be consistent yet applicable to different environments, ranging from broad public education and awareness efforts to technical discussions of research funding and findings. Pepe and several workshop participants called on the field to employ professional communications experts, as well as focus groups, to formulate the messages and gain consensus.

The resuscitation community must also focus on how to effectively communicate established messages to change behavior, said Merchant. Several workshop participants highlighted engaging experts in behavior change, marketing, and advertising when developing communication strategies that can reach diverse audiences. Howes suggested enlisting a spokesperson or an organization to lead communication efforts to represent the entire field. Davis, Merchant, and a few individuals during breakout sessions described how existing and emerging technologies,

such as mobile devices and social media, could be used to communicate messages, execute public education campaigns, and explore new research opportunities.

Effective messaging complements efforts to improve accountability for EMS and hospital system performance and establish higher standards of care—such efforts can clearly identify and explain examples of successes to emulate and failures from which to rebuild and improve, said Davis. In addition to their role in boosting public awareness, unified messaging and communication strategies are also essential components in advocacy efforts for research support and policy changes, stated one breakout group. For example, Howes highlighted the National Breast Cancer Coalition’s effort to train lay advocates, including survivors, about the science and how to talk about the more pressing issues with a wide range of stakeholder groups. Some members of another breakout group suggested that localities describe the magnitude of local challenges, progress being made, and measures of EMS and hospital performance in messaging to communities—all communities should know their numbers in terms of survival rates.

Cultivating Partnerships and Leadership

Many participants voiced support for the IOM report recommendation to establish a national cardiac arrest collaborative. Although the diverse range of organizations and stakeholders across the resuscitation field has provided a wealth of experience and knowledge, a national cardiac arrest collaborative with broad, inclusive membership could promote efficiencies and a common platform from which to advance resuscitation science and outcomes beyond the capacities of any single organization or entity, as described by Alberts, Vicky Whittemore, and several other workshop participants. Different speakers suggested that such partnerships and collaboration could help articulate shared vision, establish common goals and complementary agendas, generate consistent messaging, and promote joint initiatives. Furthermore, partnerships will be critical in defining and implementing standardized certification requirements and protocols, as well as quality improvement, performance, and outcome measures, remarked Frankel, Merritt, and others.

Workshop participants discussed the need for a flexible approach to collaborative structure and purpose in response to changes in the health policy landscape and membership composition. Whittemore discussed the evolution of collaboration in the epilepsy field, describing the transition from informal but regular communications among partners to the restructuring and rebranding of a formal collaborative that works to promote greater efficiency and impact. Albert talked about the critical sup-

port of the NIH and the National Institute of Neurological Disorders and Stroke, which provides support and infrastructure for the Brain Attack Coalition. Bonhomme described how Genetic Alliance evolved from a support group organization to a network of 10,000 organizations that advance policy, advocacy, education, and emerging scientific tools. Howes described the grassroots evolution of the National Breast Cancer Coalition, whose board includes expert volunteers from individual organizations, to advance breast cancer research and evidence-based health care in the fight to end breast cancer. Individual speakers discussed barriers to sustainable funding for not only infrastructure and day-to-day activities but also initiatives of the collaborative.

Active leadership is necessary to foster potential partnerships and collaborations and to leverage existing resources, said Lance Becker and Albert. Aufderheide said that the field will need to identify accountable, capable leaders at national, state, and local levels. Septimus and multiple breakout session participants called for champions and commitment from local hospitals and health care systems to promote cultures of improvement and excellence. Dawson, Pepe, and several workshop participants proposed more robust partnerships and active engagement across EMS agencies, EMS medical directors and personnel, public-safety answering points, health care systems, hospitals, a variety of health care providers, survivors, families, and the public to improve bystander, EMS, dispatcher, and hospital performance and to enhance cardiac arrest outcomes in communities across the United States.

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Building a National Cardiac Arrest Surveillance System

Comprehensive data collection, along with timely reporting and dissemination, are required to inform decision makers, empower stakeholders, and support improvements in cardiac arrest survival rates and outcomes (IOM, 2015). In the 2015 Institute of Medicine (IOM) report *Strategies to Improve Cardiac Arrest Survival: A Time to Act* the committee stated that “given the large health burden of cardiac arrest, a national responsibility exists to facilitate dialogue about cardiac arrest that is informed by comprehensive data collection and timely reporting and dissemination of information” (IOM, 2015, p. 8), as described in Recommendation 1 (see Box 2-1).

ENVISIONING NATIONAL SURVEILLANCE FOR CARDIAC ARREST

The Centers for Disease Control and Prevention Perspective

Robert K. Merritt, Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) joined the cardiac arrest surveillance efforts in 2004 when it sponsored the Cardiac Arrest Registry to Enhance Survival (CARES), began Robert Merritt. CARES was designed as a Web-based registry platform that captures data from 911 dispatch systems, emergency medical services (EMS) systems, and hospitals that work together to treat out-of-hospital cardiac arrest (OHCA) (CARES, 2016). When CARES was launched, it was part of a

BOX 2-1**Recommendation 1 from*****Strategies to Improve Cardiac Arrest Survival: A Time to Act*****Recommendation 1. *Establish a National Cardiac Arrest Registry***

The Centers for Disease Control and Prevention (CDC)—in collaboration with state and local health departments—should expand and coordinate cardiac arrest data collection through a publicly reported and available national cardiac arrest registry, including both out-of-hospital cardiac arrest (OHCA) and in-hospital cardiac arrest (IHCA) data, to help increase federal and state accountability for current system performance and promote actions to improve cardiac arrest outcomes.

Specifically, CDC should

- establish a cardiac arrest surveillance system for the nation that includes IHCA and OHCA data in pediatric and adult populations;
- make data publicly available through appropriate mechanisms to enable comparisons across datasets in order to increase public awareness about cardiac arrest incidence and treatments, improve accountability for emergency medical services system and health care system performance, and target interventions that will reduce disparities and improve patient outcomes;
- identify and adopt standardized definitions, criteria, and metrics (e.g., age, gender, race and ethnicity, socioeconomic status, and primary language) for cardiac arrest identification, treatment, and outcome assessment; and
- promote and coordinate the development and implementation of unique diagnostic codes for OHCA and IHCA in *International Classification of Diseases* coding models through its North American Collaborating Center, working with the Centers for Medicare & Medicaid Services and the World Health Organization.

Specifically, state, territorial, and local health departments should

- mandate tracking and reporting of all cardiac arrest events; and
- publicly report the incidence and outcomes of IHCA and OHCA within and across various areas within states and territories, taking appropriate steps to protect patient privacy and confidentiality.

SOURCE: IOM, 2015.

broader, national cardiovascular surveillance initiative being undertaken by CDC, said Merritt. Its mission is “to help communities determine standard outcome measures for out-of-hospital cardiac arrest (OHCA) allowing for quality improvement efforts and benchmarking capability to improve care and increase survival” (CARES, n.d.). Merritt indicated

that this mission was nested within CDC's overarching principles for surveillance, which focus on the collection, analysis, interpretation, and dissemination of data to advance CDC's programmatic and policy goals. However, in 2012, funding for CARES shifted from CDC to a group of private funders, including the American Heart Association, the American Red Cross, Medtronic Foundation Heart Rescue Project, and ZOLL Medical Corporation (CARES, 2016). As of the date of this workshop, CARES is a subscription-based registry that covers more than 90 million people in the United States and includes 17 state-based registries and 50 communities in 22 states (CARES, 2016).

The resuscitation activities that are currently supported by CDC are typically managed in conjunction with state and local grantees. The funding is directed toward improving surveillance efforts overall; increasing public awareness, with an emphasis on the use of cardiopulmonary resuscitation (CPR) and automated external defibrillators (AEDs); and promoting public access to defibrillation, explained Merritt. Under the umbrella of surveillance, CDC maintains two publicly available surveillance portals—Data Trends & Maps and the Interactive Atlas of Heart Disease and Stroke—that assemble and display data from various surveillance systems and data sources (CDC, 2016a,b). Merritt noted that, moving forward, the CDC surveillance initiatives will promote accelerating and enhancing the standardization of data and data exchange systems, the use of electronic health record (EHR) systems, and the implementation of electronic lab reporting and mortality surveillance systems.

Barriers and Goals for the Future

In considering the implementation of the first recommendation from the IOM's report, Merritt highlighted two main challenges for CDC. First, there are limited resources available for chronic diseases (e.g., cardiovascular diseases) overall, with greater support usually available for prevention and health promotion activities (e.g., smoking cessation and blood pressure control). Second, emerging or politically supported priorities (e.g., Ebola and Zika) often take precedence over specific areas of surveillance, such as cardiac arrest or stroke.

More broadly, Merritt described barriers that will face the resuscitation field as it attempts to establish a comprehensive national cardiac arrest surveillance system. For example, reaching consensus on goals that are both reasonable and achievable, while also agreeing on standardized performance measures, will be difficult. Merritt stated that, from a data collection standpoint, barriers are likely to arise when ensuring the following:

- data are collected in an accessible, efficient, and timely manner;
- data systems and registries are compatible and interoperable;
- data linkages across platforms are possible; and
- data can be coordinated across levels (e.g., state, county, city/town).

Merritt also noted that accounting for the underrepresentation of special populations and overcoming disparities will pose additional challenges. A priority from the CDC perspective, and also a potential challenge, is developing a publicly available portal that can organize data visually (e.g., maps) and at various levels (e.g., state, county, city/town).

In considering how to merge databases, Merritt urged the resuscitation field to agree on how much data and which measures are actually needed and what the core dataset will include. He stressed the importance of having an accurate numerator and denominator for cardiac arrest and being able to analyze that information across demographic groups. In terms of funding surveillance, Merritt reiterated that Congress and other government leaders are unlikely to support a new data system. However, developing a reportable framework through state and territorial epidemiologists—similar to the model used in the cancer community—could create a catalyst and engage the broader public health community. Merritt described how, in the cancer community, multiple registries came together through data harmonization efforts and now serve as a better source of data. In order to advance national cardiac arrest surveillance efforts, Merritt said the resuscitation field will need to establish strong public-private partnerships and develop a strategy to leverage and expand existing surveillance efforts.

In a hypothetical scenario in which Merritt received \$10 million in unrestricted funds to advance comprehensive cardiac arrest surveillance, he suggested dedicating resources to a few priority areas. His top priorities would be to establish an inclusive public-private partnership and to fund a dedicated data manager/coordinator for each state who focused solely on cardiac arrest surveillance. Next, he would allocate resources for developing a core set of standardized performance and outcomes measures, and then he would define shared technical specifications for data storage and transmission. Merritt would also ensure that the data collected were freely available and used as decision-making and accountability tools at the national, state, and local levels. Rather than starting from scratch in these efforts, Merritt urged stakeholders to build on and leverage existing public and private data systems whenever possible. In closing, Merritt emphasized that if the resuscitation field pursues making cardiac arrest a reportable event, stakeholders must unite and agree on

next steps. The field will need to determine whether to go through the Council of State and Territorial Epidemiologists, a state epidemiology mechanism, or state legislatures. Regardless of the approach used, this goal would need to be carried out in a meaningful and coordinated way, Merritt concluded.

The National Highway Traffic Safety Administration Perspective

Noah Smith, National Highway Traffic Safety Administration

The goal of the National Emergency Medical Services Information System (NEMSIS) is to “improve care through the standardization, aggregation, and usage of point-of-care EMS data at local, state, and national levels,” said Noah Smith. This multifaceted information system incorporates a documentation standard that is applied by all emergency medical technicians (EMTs) and paramedics when collecting data on patients across the country. The data captured by local EMS systems move from local repositories to state databases and then to the National EMS Database, which is fully available online and is managed by the National Highway Traffic Safety Administration (NHTSA) (NEMSIS Technical Assistance Center, 2016b). Since its inception more than 2 decades ago, NEMSIS has evolved and is currently undergoing a transition to version 3 in 2016. The version 3 standard will place more emphasis on data usage for increased public research rather than on simply collecting the data, explained Smith. The new version will encompass a larger number of data elements and will allow almost real-time data submission from ambulances responding to calls directly to the National EMS Database. Smith also pointed out that the new NEMSIS standard is Health Level-7 compliant, thus ensuring standardized data collection and enabling interoperability across other types of health care data.

The 2015 dataset from version 2 of NEMSIS covered approximately 80 percent of all 911 ground-based EMS activations in the United States, Smith said, representing more than 30 million records from nearly 10,000 EMS systems across 49 states and territories (Smith, 2016).¹ Due to the implementation process occurring predominantly within the next 2 years, Smith stated that the 2015 dataset from version 3 of NEMSIS includes several hundred thousand records from four EMS agencies across eight states. As version 3 is rolled out on a larger scale, EMS systems will collect information for dozens of data elements relevant to cardiac care,

¹ Numbers updated through personal communication, N. Smith, NHTSA, October 24, 2016.

including 19 specific data elements recorded only in the event of a cardiac arrest, said Smith (NEMESIS Technical Assistance Center, 2016a). These elements were developed in collaboration with CARES and several other stakeholders to ensure that data captured meet the needs of the resuscitation field without duplicating efforts, though they do not match exactly. These data elements will include, for example, information on etiology of the arrest, resuscitation attempts, use of CPR and AEDs, return to spontaneous circulation, and outcomes, explained Smith. The majority of the elements (13 elements) will be available at the national level, while a small portion will be available only at the state level (3 elements) or will be optional (3 elements).

Barriers and Goals for the Future

As confirmed by Smith, many of the barriers facing the resuscitation field with regard to improving surveillance are not unique to cardiac arrest or to registries, NEMESIS, EMS, or hospital care in general. The first barrier is a perceived, or actual, lack of return on investment (ROI) for data users and providers when it comes to health information technology (HIT) investments. For example, EMTs and paramedics are not always involved in planning phases when data initiatives are launched or evolve. Therefore, these key players are “left wondering whether the extra time and extra effort are actually worth it,” said Smith. At the local level, if the connections between data entry and care improvement are not made clear, these efforts are likely to fail. This challenge of perspectives may also contribute to underuse, a problem that NEMESIS has had to regularly overcome.

The second barrier, according to Smith, is that registries are not always discussed within the context of other HIT initiatives and innovations. Rethinking data collection in light of new initiatives could foster creative approaches to extract cardiac arrest data from health information exchanges and other trusted HIT infrastructures across the spectrum of care—prehospital/EMS, in-hospital, and post-discharge care. These new approaches could supersede the need for establishing another registry. Smith noted that the resuscitation field is not the only field currently weighing options to merge existing surveillance efforts. The trauma field is also considering how to create a unified registry focused on trauma care. Smith said, there are many pros and few cons to combining these efforts and resources. He offered NEMESIS as a prehospital dataset that could serve as a valuable data source for cardiac arrest surveillance efforts. Smith challenged the resuscitation field, as a whole, to devise and agree

on meaningful, incremental goals that everyone can work toward, even down to the local level across individual providers. Although there are overarching goals within the resuscitation field to improve care, enhance outcomes, and save lives, those goals may not be tangible enough to encourage action at the community level, said Smith.

Smith was also asked to consider the hypothetical scenario in which he received \$10 million in unrestricted funds to advance comprehensive cardiac arrest surveillance. He suggested first conducting a pilot test of a state-level sudden cardiac arrest registry under the most progressive, well-established state health information exchange. The registry should comprise data compiled exclusively from that exchange, thus serving as a proof of concept that would demonstrate ROI for all users, including patients. The data could be used to develop and benchmark standardized performance measures across the spectrum of care through the NHTSA-funded EMS Compass process. Smith also suggested that EMS and hospital software packages be certified together based on a set of standards related to collecting, exchanging, and submitting standard data elements on cardiac arrest. He noted that these efforts should be tied to meaningful use. Furthermore, if the resuscitation field is looking to achieve a comprehensive census of cardiac arrest, Smith suggested looking to other successful censuses in the United States, including NHTSA's Fatality Analysis Reporting System. This program pays an analyst in every state for the sole purpose of populating data into the reporting system. Smith warned against creating an added burden on health care providers in the form of data collection requirements or a cumbersome system.

Smith reiterated the value of using existing data linkage programs, such as CARES, as trusted data sources for possible expansion. "If we continue to think about registries as individual relationships between hospitals and some database in the sky, they are not going to be successful in the future," he said. Another workshop participant supported the expansion of CARES, but encouraged a more unified approach to engaging EMS systems and hospitals, rather than "the sort of guerrilla tactics [currently being used]—going EMS agency to EMS agency, hospital to hospital." The participant said that EHR vendors at both the EMS and hospital levels could be involved in developing a meaningful use approach to expanding coverage from 27 percent to 100 percent of the population. In closing, Smith encouraged the resuscitation field to collaborate with others and build on the previous successes, such as the standards that already exist within EMS, rather than starting from scratch.

Results of the National Heart, Lung, and Blood Institute's Sudden Cardiac Death Prevention Working Group

Christine Albert, Brigham and Women's Hospital

Each year in the United States, approximately 250,000 individuals suffer a sudden cardiac death, began Christine Albert.² Although sudden cardiac death is a relatively rare event with a rate of 60 to 90 per 100,000 person-years, stated Albert, it has a major impact on families and society overall (Albert, 2016; NHLBI, 2016). In the past few decades, reductions in sudden cardiac death incidence have not matched reductions in deaths associated with other types of coronary heart diseases. Albert indicated that there are a number of complicating factors that impede progress and emphasized the need for advances in prevention. For example, most of the sudden cardiac deaths occur within low-risk populations—individuals with no history of cardiac disease (55 percent of men and 64 percent of women)—making it difficult to define target populations for prevention. Additionally, a majority of cardiac arrests are not witnessed (50 percent) and/or occur in homes (70 percent), posing sizable barriers to immediate and effective treatment, asserted Albert, further emphasizing the importance of prevention (Albert, 2016).

Due to the complexity and persistence of sudden cardiac death, the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health (NIH) assembled an expert working group focused on prevention in May 2016. Albert noted that the group was tasked with identifying research barriers, considering innovative solutions, developing recommendations to advance research efforts, and establishing short- and long-term goals for preventing sudden cardiac death in the general population. The working group divided its deliberations across four subgroups and areas of focus, which resulted in the development of the following five recommendations:

- NHLBI Working Group Recommendation 1: Sudden cardiac death should be classified as a reportable condition—a recommendation, noted Albert, that is similar to recommendations coming from the resuscitation field for cardiac arrest. This recom-

² As defined in Chapter 1, sudden cardiac arrest is “a severe malfunction or cessation of the electrical and mechanical activity of the heart . . . [which] results in almost instantaneous loss of consciousness and collapse” (IOM, 2015, p. 1). Sudden cardiac death is “defined as death due to a cardiac etiology or cardiac involvement in a noncardiac disorder, in a person with or without a known pre-existing disease, and in whom the time and mode of death are unexpected” (IOM, 2015, p. 27, citing Myerburg and Castellanos, 2015).

mendation also calls for a standard lexicon, reporting procedures, death certificate elements, and postmortem examinations.

- NHLBI Working Group Recommendation 2: Use existing and new datasets (e.g., NHLBI datasets, the Patient-Centered Clinical Research Network, the Precision Medicine Initiative, cardiac arrest registries) to identify and confirm cases and subtypes of sudden cardiac death. This would require data elements that capture information on possible risk factors that preceded the death (e.g., age, health status, comorbid conditions), noted Albert.
- NHLBI Working Group Recommendation 3: Engage in collaborative analysis to compile and analyze sizeable datasets that allow for the exploration of subphenotypes, while minimizing heterogeneity, and target preventive approaches.
- NHLBI Working Group Recommendation 4: Establish a sudden cardiac death registry for adults, paralleling the Sudden Death in the Young Case Registry, which could incorporate data from autopsies or EMS and hospital records.
- NHLBI Working Group Recommendation 5: Facilitate the development and validation of scalable sensors/monitoring devices that can be used to identify risk factors and triggers of sudden cardiac death and sudden cardiac arrest.

Albert observed that having multiple databases often leads to inefficiencies because the data may be collected in different ways based on different definitions, which then leads to different answers to the same research questions. Registries focus on the variables connected with the arrest, said Albert, whereas epidemiologists want to know more about the factors preceding the event. This disconnect hinders opportunities for collaboration and melding data.

Next, Albert noted that both cardiac arrest and sudden cardiac death have a range of diverse characteristics. She again called for making sudden cardiac death a reportable condition and described the factors that would be required to achieve that goal. Albert said that a set of rudimentary details about what happened before the person died (e.g., how long did symptoms last, medical history) would need to be collected in a standardized way to facilitate collaborative study. She emphasized the importance of common definitions for cardiac arrest and sudden death, which would need to be consistently applied across death reporting and death certificates—admittedly a huge undertaking. A more cost-effective approach to improving surveillance of sudden cardiac death, Albert suggested, would be to incorporate sudden cardiac death into future large-scale cohort studies.

To merge databases effectively, leadership and collaboration will be

needed. Albert said the accuracy of the data captured in the database needs to be a priority. She suggested that CARES could be expanded, but that the covered population would also need to be expanded, as well as the areas in which data are collected. For example, the registry would also need to collect data on sudden death and the circumstance of the arrest, said Albert.

The Paul Coverdell National Acute Stroke Registry: How to Overcome Shared Pitfalls

Michael Frankel, Emory University

Sometimes it is easy to lose sight of the fact that cardiac arrest is as much about the brain as it is the heart, Michael Frankel observed. Cardiac and neurologic outcomes are equally important and cannot be viewed as being mutually exclusive. Frankel urged leaders, researchers, and other stakeholders to better integrate these two organ systems and outcomes when discussing data collection strategies. Like stroke, cardiac arrest must also be viewed from the public health perspective. In Georgia, for example, the stroke community applies an interconnected model for improving public health (see Figure 2-1). Disease surveillance and basic science discoveries serve as a basis for decisions at the public health level. The work of NIH's StrokeNet—a collaborative of 25

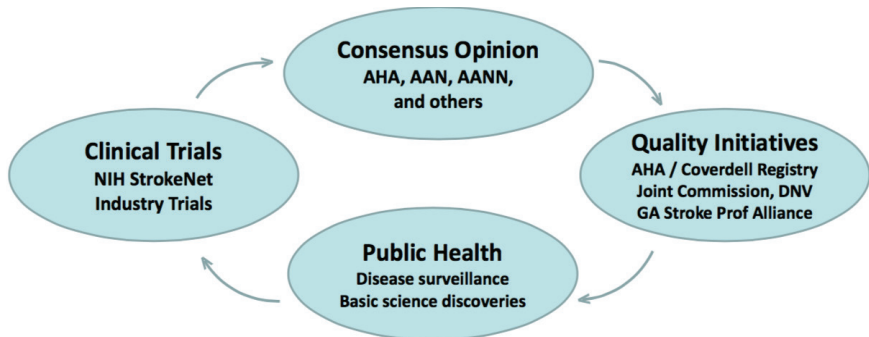


FIGURE 2-1 A connected view of improving public health in stroke in the state of Georgia.

NOTE: AAN = American Academy of Neurology; AANN = American Association of Neuroscience Nurses; AHA = American Hospital Association; DNV = Det Norske Veritas; GA = Georgia; NIH = National Institutes of Health.

SOURCE: Presented by Michael Frankel, July 11, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*.

regional stroke centers that enhance recruitment for clinical trials—combined with evidence from the clinical trials are used to inform consensus opinions. In turn, the consensus opinion statements released by professional organizations stimulate quality and education initiatives at the local and hospital levels, such as those that operate under the Coverdell Stroke Registry, the Georgia Stroke Professionals Alliances, and the Joint Commission.

As described in previous IOM work, there is “a gap between what we know and what we do,” said Frankel, and this is the gap that the Coverdell Stroke Registry is trying to bridge. Despite its name, the Coverdell Stroke Registry is not a disease surveillance registry; it is a surveillance tool dedicated to quality improvement. CDC launched the registry in 2001 with funding allocated by Congress in honor of Senator Paul Coverdell (R-GA), who died following a stroke in 2000. The overarching goal of the state-based registry, continued Frankel, is to collect data on stroke care in order to promote the implementation of the highest quality care and reduce mortality. The registry began as a pilot study run by Emory University, but today includes hospitals in nine states.

Challenges and Opportunities

The Coverdell Stroke Registry collects data on a set of evidence-based quality indicators in areas that include the timeliness of treatment, use of prophylactic treatments during hospitalization, screening for other risk factors, stroke education, assessment for rehabilitation, and discharge treatment plans. Future efforts will focus on data collection beyond hospitalization and into the recovery phases by linking datasets. One of the biggest challenges, said Frankel, is capturing data on long-term neurologic outcomes. Fragmentation and silos across the continuum of care from before to after hospitalization pose major barriers, and hospitals will need to be more engaged in post-hospital data collection. However, dwindling resources and a lack of leadership within hospitals continue to present sizable difficulties that the Coverdell Stroke Registry must overcome. A number of data-related obstacles have also presented challenges, said Frankel. For example, lack of rigor and validation, along with missing data, undermine improvement efforts. Data-sharing limitations associated with the Health Insurance Portability and Accountability Act also pose additional regulatory barriers, noted Frankel.

In part, the successes of the Coverdell Stroke Registry in Georgia can be credited to the collaborative efforts among the American Heart Association, the American Stroke Association, the Joint Commission, and participating hospitals, said Frankel. If existing registries (e.g., CARES, Get With the Guidelines) are to be leveraged in building a cardiac arrest

surveillance system, strong partnerships will need to establish standardized quality and outcome metrics and merge existing data infrastructures. In closing, Frankel suggested that the CDC model of funding for the stroke registry could be used to select a sample of representative states to participate in a registry designed for both surveillance and quality improvement efforts.

Cognitive Computing as a Cardiac Arrest Surveillance Strategy

Laura Langmade, IBM Watson Health

Watson Health is a cognitive computing system that is capable of understanding, reasoning, and learning, according to Laura Langmade. For health care, structured data include easily quantifiable data points that can be found in EHRs, such as vital signs and lab results, whereas unstructured data refers to blocks of text found in published literature, social media, and images. In practical terms, this means that Watson could read and understand the more than 7,000 articles generated from a PubMed literature search for cardiac arrest risk factors faster and more efficiently than the average person. This is new and exciting territory, asserted Langmade, given the large body of literature that is produced every day. Watson is also able to analyze available data and offer evidence-based care options for providers' considerations, thus demonstrating its ability to reason. Cognitive computing systems, such as Watson, are also dynamic and able to learn over time based on inputs—a type of collaboration between technology and humans, remarked Langmade.

Cognitive systems excel at a number of tasks that are incredibly useful in the practice of medicine—pattern identification, natural language processing, locating information and knowledge, and eliminating bias. Through computing, all of this can be accomplished at high rates of speed and with endless capacity, indicated Langmade. Watson could also be used by researchers to glean insights from numerous data sources (Chen et al., 2016). Data become powerful when useful insights, or actionable knowledge from data, can be found. Insights in the future could help guide decisions about data elements and quality metrics that need to be collected moving forward. Although Watson is capable of many things that could reshape medicine, Langmade pointed out that several traits are uniquely human and cannot be substituted by technology—having and applying common sense, morals, ethics, compassion, and imagination; managing abstraction; and making generalizations.

As part of Watson Health's efforts, Langmade also noted that IBM acquired a data management platform called Explorys, which can be deeply integrated into EHR systems and allows various levels of analytics and reporting, population assessments, and application of risk models. Among other things, Explorys uses big data across health care settings to help providers improve the delivery of health care (IBM, 2016). Additionally, to support Vice President Joe Biden's Cancer Moonshot Initiative, IBM Watson Health has established a public-private partnership with the Department of Veterans Affairs, which provides Watson for Genomics to the organization in an effort to help expand their precision medicine efforts to combat cancer.

Barriers and Lessons Learned

When considering how elements from cognitive computing and technological advances could be applied to the development of a cardiac arrest registry, Langmade encouraged developers to think about how the data are generated and collected, how those data will be mapped and moved across systems, how the data can be scrubbed of technically implausible information, and how to accomplish ongoing monitoring and validation of the data. Langmade identified three main barriers that will need to be overcome in order to design a national registry: the diversity of data sources, the volume of data, and the variety of data.

Data exist all along the chain of survival—from collapse and initial resuscitation efforts to the 911 call and EMS arrival and through hospital and postdischarge care. This diversity of data may result in silos of information that need to be bridged and integrated. However, Langmade described this as not only a barrier but also an opportunity to gain new insights from connections that are made across various datasets. The sheer volume of data generated across all cardiac arrests nationwide is going to be a challenge, noted Langmade. The strengths and weaknesses of the existing datasets should be evaluated before making a decision about how to merge the databases. The variety of data—both structured and unstructured—will need to be managed. Overcoming these barriers could be possible through technological advances, such as cognitive computing systems, and through public-private partnerships. Langmade also emphasized the importance of collaborating with the public and viewing the public as a key stakeholder along the way, suggesting that merging databases could lead to new insights that are not possible with the current fragmentation.

BREAKOUT SESSION REPORT: ENVISIONING NATIONAL SURVEILLANCE

Lance Becker and Dianne Atkins, Planning Committee Members³

Lance Becker and Dianne Atkins led the two breakout sessions focused on envisioning national surveillance and strategies for advancing the IOM's recommendation on surveillance. In considering possible barriers for implementation, Becker noted that large quantities of data feed into numerous registries. However, the data are not always shared, and there is not a standardized dataset that is collected nationally for cardiac arrest. A cardiac arrest survivor pointed out that, although crime statistics—including murder rates—are readily available and reported throughout every community in the United States, cardiac arrest statistics are difficult to obtain. Some breakout session members highlighted the need to be able to track 100 percent of the population in order to document every cardiac arrest, regardless of location of arrest, treatment administered, and whether or not EMS was called. Atkins reported that interoperability challenges across EMS and hospital records will need to be solved in order to comprehensively collect data from prehospital through post-hospital care and outcomes.

Both groups considered different options to enhance a cardiac arrest surveillance system. There is no definition of an optimal registry, stated Becker. Atkins's breakout session considered the benefits of building a new national dataset. Some breakout session members suggested that a new dataset, populated by mandatory reporting and transparent processes, could lead to a cost savings in the long run. Developing a national surveillance system could be a resource-intensive process, reported Becker. Atkins noted that much of the necessary work has already been done; thus building a database from scratch could be a waste of valuable resources.

Some members of Becker's breakout group encouraged an efficient, scalable state-based registry model. A few participants presented CARES as an existing, rigorous, affordable tool that has had documented, positive impacts on processes and outcomes. CARES uses a secure platform and produces high-quality data and results. However, there are some downsides to building on existing initiatives, noted Atkins. A few breakout session members echoed Albert's concerns about data fragmentation

³ Breakout session presenters were asked to summarize the major ideas and opinions proposed by individual participants during their respective breakout sessions. Individual statements described below are not necessarily the position of the presenter and should not be interpreted as consensus statements from the breakout group as a whole or of the National Academies of Sciences, Engineering, and Medicine.

and accuracy. Some individuals also noted that funding and levels of collaboration are variable, and more importantly, the existing registries are all voluntary. Some breakout group members suggested that advancing surveillance would be easier if cardiac arrest was established as a mandatory reportable condition.

Both Becker and Atkins highlighted the need for accountability and sustainability, noting that funding and sustainability are always inextricably linked. Several participants in Atkins's group suggested applying the Centers for Medicare & Medicaid Services model in which providers are not paid unless they participate in measurement and process requirements. Members of Atkins's breakout group also encouraged a built-in feedback feature that would allow EMS, hospitals, and communities to track their progress. Becker and Atkins noted that data entry and reporting must not be onerous, and any efforts to expand surveillance would need to be cost-effective. Atkins underscored the importance of defining a minimum dataset with optional elements that could be added, depend-

BOX 2-2

Examples of Potential Partners for Building a National Cardiac Arrest Surveillance System

- **Federal Government Agencies:** Centers for Disease Control and Prevention, Department of Health and Human Services, Department of Homeland Security, Food and Drug Administration, National Highway Traffic Safety Administration, National Institutes of Health, and others.
- **State and Local Agencies and Entities:** health departments, law enforcement, emergency medical services (EMS) systems, health care systems, hospitals, community organizations, and others.
- **Professional Organizations and Nonprofit Organizations:** American Academy of Pediatrics, American College of Emergency Physicians, American Heart Association, American Hospital Association, American Public Health Association, American Red Cross, American Stroke Association, Heart Rhythm Society, National Association of EMS Physicians, and many others.
- **Industry:** Google, IBM Watson Health, biomedical and pharmaceutical companies, device manufacturers, electronic health record vendors, data standards organizations, and others.
- **Existing Registries for Both In- and Out-of-Hospital Cardiac Arrest**
- **Insurers/Payers**
- **The Public**

SOURCE: Presented by Dianne Atkins and Lance Becker, July 11, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*.

ing on available time and resources regardless of format, and emphasized how data linkages and automated data entry could be used to minimize time requirements. Becker emphasized that all communities need to be given an opportunity to improve their chains of survival and outcomes—building on lessons learned from better cardiac arrest surveillance.

Both breakout sessions were asked to brainstorm lists of potential partners to engage in building a national cardiac arrest surveillance system. Atkins pointed out that the existing datasets and registries have already demonstrated value in terms of building partnerships and documenting changes in disease patterns. Box 2-2 includes examples of the types of stakeholders that could be approached. Becker and some members of his breakout group suggested that emphasis be placed on government agencies with a degree of accountability and nongovernmental organizations with missions directly related to cardiac arrest.

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Advancing Cardiac Arrest Research and Translation

Knowledge gaps related to the etiology and pathophysiology of cardiac arrest, and the efficacy and use of existing treatments, impede additional progress in reducing mortality and improving cardiac arrest outcomes (IOM, 2015). A collaborative effort across the resuscitation field and translational research spectrum will be required to overcome persistent knowledge gaps, advance resuscitation science, and ultimately save lives, as described in Recommendations 6 and 7 (see Box 3-1).

CHALLENGES AND OPPORTUNITIES IN RESEARCH AND TRANSLATION

Turning Discovery Science into Public Health Impact: Seizing New Opportunities in Cardiac Arrest Research

*Gary Gibbons, National Heart, Lung, and Blood Institute,
National Institutes of Health*

One element of the National Heart, Lung, and Blood Institute's (NHLBI's) mission is to support investigator-initiated programs that draw on the collective intelligence of experts across a variety of disciplines in order to advance the prevention and treatment of heart diseases, said Gary Gibbons. To this end, NHLBI's research portfolio spans the entire translational research spectrum (see Figure 3-1) to ensure that discovery science leads to enhanced prediction, prevention, and treatment of dis-

BOX 3-1**Recommendations 6 and 7 from
*Strategies to Improve Cardiac Arrest Survival: A Time to Act*****Recommendation 6. Accelerate Research on Pathophysiology, New Therapies, and Translation of Science for Cardiac Arrest**

In order to identify new, effective treatments for cardiac arrest, the National Institutes of Health (NIH), the American Heart Association, and the U.S. Department of Veterans Affairs should lead a collaborative effort with other federal agencies and private industry to build the nation's research infrastructure that will support and accelerate innovative research on the causal mechanisms of onset, pathophysiology, treatment, and outcomes of cardiac arrest. These actions should

- strengthen laboratory, clinical, and translational resuscitation research support to levels commensurate with the public health burden of cardiac arrest for adult and pediatric populations across federal agencies, including NIH institutes; and
- establish a balanced and comprehensive portfolio of grants across the full spectrum of science translation to encourage the development and application of novel and efficient research strategies and innovative trial designs in preclinical, clinical (e.g., exploratory and hypothesis-generating studies), and population-based resuscitation research.

Recommendation 7. Accelerate Research on the Evaluation and Adoption of Cardiac Arrest Therapies

The National Institutes of Health should lead a collaborative effort with the U.S. Department of Veterans Affairs, the Agency for Healthcare Research and Quality, and the Patient-Centered Outcomes Research Institute to prioritize health services research related to the identification, evaluation, and adoption of best practices; the use of innovative technologies (e.g., mobile and social media strategies to increase bystander cardiopulmonary resuscitation or automated external defibrillator use); and the development of new implementation strategies for cardiac arrest treatments.

SOURCE: IOM, 2015.

eases and conditions—which ultimately can improve the health of the nation. Findings at each phase can expand knowledge about the nature of heart disease and sudden cardiac arrest and death, Gibbon indicated.¹ For example, discovery science explores the fundamentals of how the

¹ As defined in Chapter 1, sudden cardiac arrest is “a severe malfunction or cessation of the electrical and mechanical activity of the heart . . . [which] results in almost instantaneous loss of consciousness and collapse” (IOM, 2015, p. 1). Sudden cardiac death is “defined as death due to a cardiac etiology or cardiac involvement in a noncardiac disorder, in a person

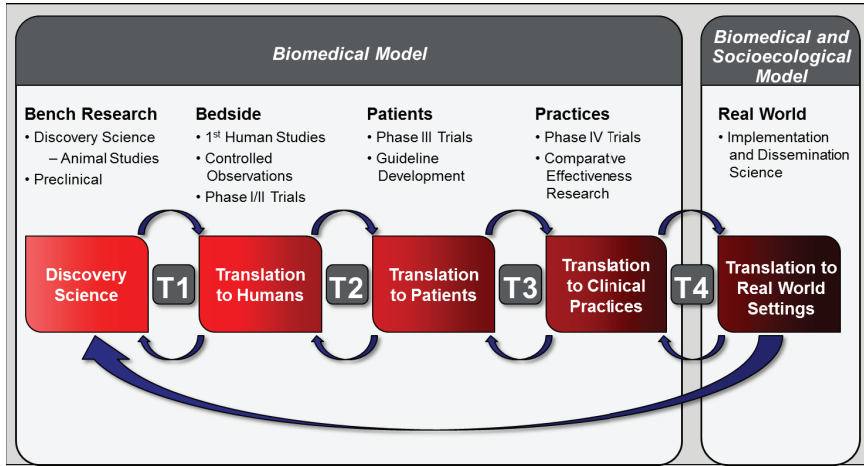


FIGURE 3-1 Phases of the translational research spectrum.
 SOURCE: Presented by Gary Gibbons, July 11, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act* (adapted from Mensah, 2013).

heart and its electrical system function. Translating discovery science into humans (T1) provides insights into the underlying pathobiology and molecular basis for heritable mutations that may predispose a patient to certain cardiac arrhythmias and death. Translating findings at this level into treatment strategies (T2) expands opportunities to more effectively intervene and change the natural history of the disease. The latter phases of the spectrum (T3 and T4) include efforts to establish efficacy of new treatments, noted Gibbons, and to ensure that resuscitation science guides health care practice in real-world settings and communities.

New technologies and tools are expanding opportunities to strengthen researchers’ understanding of the pathophysiology of cardiac disease and arrest, said Gibbons. For example, the ability to sequence an entire human genome, map layers of its proteome and epigenome, and characterize the molecules of the heart and its systems in relatively short time frames has unlocked a wealth of knowledge. Stem cells can now be manipulated to study the electrical system, which could provide a better understanding of the risk factors, triggers, and possible treatments for fatal arrhythmias, Gibbons noted. Furthermore, mobile technologies and sensors—such

with or without a known pre-existing disease, and in whom the time and mode of death are unexpected” (IOM, 2015, p. 27, citing Myerburg and Castellanos, 2015).

as smart phones, watches, and health monitors—are creating new data sources and mechanisms to study the onset and treatment of sudden cardiac arrest and death, prior to arrival in the emergency department. Gibbons suggested that sensor technologies through continuous cardiac monitoring could reveal what happens before cardiac arrest, in addition to connecting individuals trained in cardiopulmonary resuscitation (CPR) to those experiencing a cardiac arrest and to automated external defibrillators. He asked workshop participants to help NHLBI identify the most effective ways to employ mobile health technologies and precision medicine to study cardiac arrest and the subphenotypes associated with resilience and susceptibility.

NHLBI is building on its legacy research portfolio to support initiator–initiated research and research networks that are redefining resuscitation science and how it can influence patient care across health care settings. Gibbons cited a number of National Institutes of Health (NIH) activities that related to the study of cardiac arrest, including the following:

- The Strategies to Innovate EmeRgENcy Care Clinical Trials Network (SIREN) is a new collaborative network among NIH’s Office of Emergency Care Research, the National Institute of Neurological Disorders and Stroke, NHLBI, the Department of Defense (DoD), and others to advance emergency care clinical trials.
- NHLBI’s Trans-omics for Precision Medicine (TOPMed) program uses genome sequencing and -omic and phenotype data in large-scale NHLBI cohort studies (e.g., Women’s Health Initiative, Framingham Heart Study) to explore the underlying pathophysiological causes of disease.
- NIH’s new Precision Medicine Initiative[®] Cohort Program,² which aims to enroll more than 1 million participants in a process that generates data, develops data standards and interoperability, leverages electronic health records (EHRs), and uses mobile and sensor technologies to better predict and prevent disease.

In the spirit of collaboration and information exchange, Gibbons urged workshop participants to consider the most important scientific questions to ask in preclinical models and clinical trials in order to reduce cardiac arrest mortality. Gibbons noted that NHLBI is in the final stages of its strategic visioning process, which used crowdsourcing to establish an agenda for the next 5 to 10 years. One identified objective was to “develop and optimize novel diagnostic and therapeutic strategies to prevent, treat,

² On October 12, 2016, NIH announced that the Precision Medicine Initiative[®] Cohort Program had been renamed as the *All of Us*[™] Research Program.

and cure HLBS [heart, lung, blood, and sleep] diseases,” (NHLBI, 2016, p. 9), including sudden cardiac arrest and death.

In response to an audience question, Gibbons noted that the ultimate goal of improving outcomes for patients is shared across all potential stakeholders and numerous mechanisms to collaborate and advance specific goals (e.g., data sharing or precision medicine). In closing, he encouraged the participants to think about strategies that can be used to leverage existing systems and datasets to transcend silos and work toward wide-scale adoption of effective treatments for cardiac arrest.

Creating a Research Network to Build Solutions

Natasha Bonhomme, Genetic Alliance

Genetic Alliance is a health advocacy organization that was formed 30 years ago as a resource for support groups and individuals who were interested in starting foundations, contributing to research, or getting involved with a particular health condition. Today, Genetic Alliance has a network of more than 10,000 organizations, individuals, and agencies that are involved in policy, advocacy, education, and research, said Natasha Bonhomme. As part of Genetic Alliance, these organizations are committed to individuals, families, and communities and to ensuring that people are at the center of research efforts.

In collaboration with its stakeholders and communities, the Genetic Alliance has created a highly customizable registry platform called the Platform for Engaging Everyone Responsibly (PEER). PEER was designed to collect privacy-assured health information, and at its core is meant to be engaging, consumer centric, collaborative, and dynamic—connecting participants with research in a meaningful way. Currently 40 different communities are using PEER. These communities range from disease-specific advocacy organizations to a town in Pennsylvania that wanted to follow the potential health implications of local fracking.

A cornerstone of PEER is creating an environment of trust, said Bonhomme. Trust is garnered, in part, by allowing organizations to brand the platform as their own and fully integrate it into their website. This gives individuals a sense of familiarity and trust when they decide to participate and register. Trust is also fostered through privacy layers and by empowering participants to make decisions about how their personal information is used. Because of varying privacy concerns and preferences, the platform allows individuals to customize their own privacy and health data-sharing settings, thus determining exactly what information is included and shared and under what circumstances. Some individuals may be willing to share everything, while others may be more conser-

vative and only willing to share information when they are asked. The ability to make these decisions and knowing that their information is protected solidifies participants' trust in the system. When more than 12,000 users were asked about their level of trust in PEER, 90 percent reported being extremely confident and having complete trust in the system.

Genetic Alliance has also launched a program called Community Engaged Network for All (CENA), which is supported by the Patient-Centered Outcomes Research Institute (PCORI) and uses PEER. Currently in the second phase of funding, CENA is actively engaging 12 disease-specific advocacy organizations that represent 32 health conditions. The goal is to put patients at the center of the research paradigm by developing community- and participant-driven studies. Patients, clinicians, researchers, and other stakeholders are actively working together to identify feasible patient-centered research questions and to design studies with patient-centered protocols. CENA is using PEER and another registry platform called Mosaic to build cohorts of participants for the studies.

Bonhomme said the notion of merging data collection efforts to further research is a powerful one. When there are too many registries or datasets to populate, the users see the process as a burden and become disinterested. However, when you combine efforts, as Genetic Alliance did with PEER, disparate groups that thought they had nothing in common came to realize that there is often a lot of overlap in both the experiences they share and their data needs. Bonhomme suggested starting with a shared infrastructure for collecting common data points that can then be tailored and expanded, as needed, to collect data points that are unique to cardiac arrest.

Challenges and Opportunities

Bonhomme noted that there are still many challenges in getting interested individuals fully integrated into research and determining where consumers and caregivers fit into research efforts. Regardless of their role in research, building trust and trustworthiness among participants and researchers will be critical to success. Current research infrastructures are designed for making transactions, not always building trust and relationships. Participants should feel like they are playing an active role in research, not just a one-sided interaction in which they supply data to researchers without further interaction. Bonhomme emphasized the importance of patient engagement in the research process and highlighted PCORI and the NIH Personalized Medicine Initiative. This type of engagement can humanize data and connect stories and faces to data points. In this vein, Bonhomme called for more real-life models of patients and families being truly involved in the research process. Valuable lessons

can be learned from these experiences and applied to future efforts to actively involve patients in the research enterprise.

Public–Private Partnerships as Driving Forces for Innovative Treatments and Research Policies

Nigel Hughes, Janssen Research and Development

A number of public–private partnerships in the European Union (EU) could serve as exemplars for advancing cardiac arrest research and surveillance in the United States, said Nigel Hughes. For example, the Innovative Medicine Initiative (IMI) (IMI, 2016), which was established in 2008 across 28 European countries, has the overarching goal of accelerating access to innovative medical therapies for EU citizens. The initiative supports programs across all diseases and health conditions and also across the spectrum of care from diagnostics to therapeutics. Perhaps one of the largest public–private partnerships in the world, Hughes noted that the budget for the first iteration of the initiative was €3 billion, which was split between the European Federation of Pharmaceutical Industries and Associations and the EU. As partners, the pharmaceutical industry agreed to match the resources provided through in-kind services and resources, such as technology, expertise, time, and other types of support. The second iteration of IMI was launched in 2014 with a slightly larger budget and is already supporting various programs throughout the EU.

One of the ongoing, IMI-supported public–private partnership programs is the European Medical Information Framework (EMIF) (EMIF, 2016). This 5-year initiative, which started in 2013, has a budget of €56 million and engages 58 partners from 14 EU countries. Hughes indicated that EMIF is developing a governance and technology platform, which will allow researchers to identify, access, assess, and use a variety of data sources, such as EHRs, cohort datasets, registries, and payer datasets. Within the initiative, two subgroups are working to identify early biomarkers using the EMIF platform and processes—metabolic diseases, such as obesity and diabetes, and Alzheimer’s disease. The research efforts are driven by cohort and population and have already resulted in a number of publications describing outcomes. At the end of the 5-year initiative, the goal is to have a fully sustainable platform, along with streamlined processes (e.g., contracting, ethics committees) that can be used in other disease areas.

The Electronic Health Record for Clinical Research (EHR4CR) was an IMI-supported project that is now transitioning to the sustainable, scalable part of its life cycle, said Hughes (EHR4CR, 2016). With eight partners involved, it is being supported by a number of pharmaceutical

companies in collaboration with hospital networks across the EU. The purpose of this program was to establish a data exchange infrastructure or the *digital plumbing* that, as Hughes described it, would allow hospitals and medical systems across Europe to share data under the appropriate set of conditions and criteria (e.g., legal, ethical). In turn, the data shared across systems could then be used to promote clinical research. For example, if a researcher wanted to assess a clinical trial protocol, the researcher could access the hospital network platform and compare existing patient populations against the exclusion and inclusion criteria in the protocol. This assessment, said Hughes, would hopefully accelerate the time required to get to the testing phase and eliminate some of the uncertainties about enrollment.

In the United States, NIH's Accelerating Medicines Partnership is a 5-year public–private partnership program launched in 2014 that is developing knowledge portals (NIH, 2016). These portals will be used to collect and assemble genotypic and phenotypic data for translational research purposes. Similar to EMIF, this partnership is currently focused on three disease areas: Alzheimer's disease, type 2 diabetes, and autoimmune disorders, including lupus and rheumatoid arthritis. This provides a model of collaboration, bringing together partners from all over academia, clinical settings, and industry, said Hughes.

Lessons Learned and Successes

In response to a comment, Hughes agreed that in order to advance research, the resuscitation field needs a large-scale data source that can be used to follow patients over decades, not just years or 30 days. Hughes noted that differing views of confidentiality and privacy in Europe provide linked data opportunities that are not currently possible in the United States. Some countries have been able to link health data, social data, census data, and other types of data, offering a complete picture, valuable context, and the ability to follow individuals longitudinally over the course of their lives. Hughes urged a reconsideration of data collection and privacy in the United States. In most countries, organ donation is managed using an opt-in or opt-out system. Hughes said the research community should consider developing a similar system for altruistic data donation and sharing that could be used to benefit health research. However, there is some degree of persistent reticence about data sharing, linkages, and privacy—even among health care providers and researchers—that prevent this from happening, said Hughes.

Data from industry-funded clinical trials are limited to the clinic-based, observational data that cannot always provide context and background. Public–private partnerships could expand the availability of data

to encompass cohorts, allowing researchers to better understand the natural history of the disease and what outcomes are possible. This broader view could lead to more translational research and the development of new biomarkers. Although most people only think about the funding aspects of public–private partnerships, there are many other benefits for all collaborators. For example, industry can also share goals, expertise, skills, technologies, and research outputs with the public side of the partnership. Hughes said the more productive approach to public–private partnerships goes beyond funding and requires the development of long-term, longitudinal partnerships that would engage clinicians, academics, industry, and patient groups.

Hughes stated that, through all of these partnership efforts, the most important lesson is that “it’s not about data, it’s not really about the technology—it’s all about the people.” Another element for success is optimal project management of large-scale programs. To effectively align disparate agendas, he said, the needs of the stakeholders must be considered in the planning phases, and leaders need to understand what the individual agendas are before trying to merge and align those agendas. Hughes described the need for harmonized data sources to ensure efficient access, saying that “there are only two types of data to worry about—data you own and data you don’t own—and it’s the data you don’t own that [present] the challenge.” He also urged stakeholders not to underestimate the time required to develop real-world data programs. In closing, Hughes reflected on successes across recent public–private partnership efforts. He highlighted that today there is a much larger pre-competitive collaboration of industry partners, better alignment between industry and academic research and development, and improved harmonization of data sources and information portals. Overall, industry and academia are open to more collaborative models of research and agree that therapeutic research efforts can no longer be pursued in isolation.

Environments and Conditions That Facilitate Cardiac Arrest Research Through Better Coordination, Oversight, and Strategy

Demetris Yannopoulos, University of Minnesota

The complexity of cardiac arrest at the pathophysiological level has resulted in many unanswered scientific questions, began Demetris Yannopoulos. For example, the physiology of low and no blood flow situations that lead to generalized tissue hypoxia or anoxia followed by reperfusion is not well understood, especially given the multisystem involvement of this process (e.g., heart, brain, lungs, kidneys). These complex challenges surpass the singular expertise of any of the traditional

scientific fields and may require a large national strategic effort—similar to the Human Genome Project or the BRAIN (Brain Research through Advancing Innovative Nanotechnologies) Initiative—with congressional support in order to make progress. A national fund dedicated to cardiac arrest science and resuscitation could be established by pooling resources from major funding agencies (e.g., NIH, DoD, PCORI), organizations (e.g., National Science Foundation, American Heart Association), and corporate foundations, suggested Yannopoulos. The resources from this national fund could then be allocated strategically for projects with a clear purpose. Yannopoulos emphasized that no progress can be made or improvements achieved without adequate resources.

Across cardiac arrest clinical trials, Yannopoulos highlighted a persistent challenge with demonstrating statistical power, *p* values, and the magnitude of effect, which impact how study findings are interpreted and judged. When therapies benefit patients but fail to reach the desired *p* value (≤ 0.05), the findings are often discarded, and the field remains stagnant. For example, a recent study by Moler and colleagues (2015) tested the use of therapeutic hypothermia following cardiac arrest in a population of 260 children. The *p* value was 0.14, indicating that the therapeutic hypothermia was not effective. However, 20 percent of children who received the hypothermic treatment survived, whereas the survival rate without the treatment was only 12 percent. Yannopoulos asked researchers to consider exactly what a successful outcome in resuscitation science looks like if a 66 percent higher chance for survival in children is dismissed based on a study that overestimated the effect of the treatment. Referring to a statement from Andrew Gelman, a statistician, Yannopoulos noted that, although physicians and scientists want certainty, that is not always a possibility. He also warned of the overreliance on the significance of *p* values and pointed out that the American Statistical Association recently released a statement on the inappropriate use of *p* values in research, which also included guidelines on the appropriate application of *p* values (ASA, 2016; Baker, 2016).

Accounting for confounders, such as nearly uncontrollable variation (e.g., quality of manual CPR) and the presence of unknown variables (e.g., coronary artery stenosis), poses sizable design challenges to cardiac arrest studies. Confounders can significantly affect study findings and the subsequent interpretation of those findings. As noted by Yannopoulos and colleagues (2015), the quality of CPR represents a significant effect modifier of outcomes—good-quality CPR is beneficial, whereas low-quality CPR is harmful, and its interactions with proposed interventions can be difficult to model or predict. Because the quality of manual CPR is difficult to effectively govern, Yannopoulos indicated that standard, manual CPR techniques are an unreliable control for studies testing alternate

CPR techniques, such as the impedance threshold devices developed by researchers from the Resuscitation Outcomes Collaborative.

Existence of underlying coronary artery stenosis also represents a notable challenge to cardiac arrest studies. The degree of blockage is directly related to the ability of achieving return of spontaneous circulation following a cardiac arrest. Therefore, the uneven distribution of patients with stenosis could mask the effect of a therapeutic prehospital intervention being tested when survival rates are used as the outcome measure. Yannopoulos said that having, arguably, one of the most important contributors to survival be an unknown, the untreated variable is a problem that may not be solved by randomization and that will ultimately affect the evaluation of the study results. Yannopoulos and colleagues (2016) tested an intervention that involved getting eligible patients to a catheterization laboratory for identification and appropriate treatment for stenosis (e.g., extracorporeal membrane oxygenation [ECMO]) and percutaneous coronary intervention [PCI] within 2 hours of cardiac arrest. The researchers found a significant increase in survival and positive outcomes when this alternate approach to advanced cardiac life support was used—55 percent survival to hospital discharge and 50 percent with good neurological outcomes compared with less than 9 percent of controls following the current guidelines (Yannopoulos et al., 2016). Yannopoulos argued that, unless the scientific community tries to identify and treat the underlying cause of arrest, prehospital interventions might not reliably demonstrate an impact on survival rates when studied.

Opportunities for Advancing Cardiac Arrest Research

Advancing cardiac arrest research will require funding and new approaches to study design, said Yannopoulos. First, the scientific community and the nation must come together and “declare war on cardiac arrest.” He added that a united front will also be needed to establish a national initiative that combines resources from funding agencies, organizations, and industry. The funding should be used to review, evaluate, and fund basic, translational, and clinical research in the resuscitation field, commented Yannopoulos. In terms of study design, confounders and underlying determinants of cardiac arrest outcomes need to be considered and factored into the study design, said Yannopoulos, noting that clinicians and statisticians need to be part of the discussion and decisions regarding what level of significance, chance, and certainty are acceptable when considering the possible benefit to patients. Finally, said Yannopoulos, the nihilism related to resuscitation practice needs to be decreased—moving away from the mandated 0.05 p value.

BREAKOUT SESSION REPORT: ACCELERATING RESEARCH AND TRANSLATION

Jeremy Brown and Arthur Sanders, Planning Committee Members³

Jeremy Brown and Arthur Sanders facilitated the two breakout sessions that discussed accelerating research and translation in response to Recommendations 6 and 7 in the Institute of Medicine's report (see Appendix A). The two groups considered barriers and methodological challenges to overcome, partners to engage, and possible funding strategies to fulfill the vision of advancing resuscitation research and translating that research into high-quality cardiac arrest care. Some members of the breakout sessions identified a number of alternative research methods that could be used to respond to methodological limitations and improve resuscitation research. For example, the resuscitation field could support the broader use of adaptive trials, stratified patient groups, and individualized protocols that are tied to the principles of patient-centered research. Sanders echoed the call for the development and application of standardized definitions to guide cardiac arrest research and surveillance.

Brown and Sanders both encouraged greater focus on implementation science to ensure that research findings are reaching patients and being used to improve outcomes across the United States. Implementation science can also be used to identify practice gaps, said Sanders, and determine how disparities—including regional variation—can be remedied. The resuscitation field needs a better understanding of why some communities, hospitals, and emergency medical services systems demonstrate significantly better outcomes when compared with others and what strategies can be easily transferred from those benchmark communities and systems, he said. Sanders said the goal should be to identify and promote the adoption of effective, evidence-based practices nationwide.

As with surveillance initiatives, funding is a serious stumbling block for advancing research, Brown noted. Some members of Brown's breakout group highlighted a number of areas where a lack of funding is particularly problematic. For example, a lack of funding limits opportunities for targeting funding toward specific areas of research, implementing evidence-based findings, investing in the next generation of cardiac arrest researchers, and exploring new research methodologies. In line with the national funding initiative that Yannopoulos described, some members of the breakout sessions suggested further exploration of a bundled fund-

³ Breakout session presenters were asked to summarize the major ideas and opinions proposed by individual participants during their respective breakout sessions. Individual statements described below are not necessarily the position of the presenter and should not be interpreted as consensus statements from the breakout group as a whole or of the National Academies of Sciences, Engineering, and Medicine.

ing mechanism that would allow funds to be allocated to agreed-upon research goals. The allocation of funds could evolve as the research needs and priorities shift, noted some individuals.

Given current and projected budget limitations, especially at NIH, Brown's group discussed alternate strategies to gain further financial support for research. He suggested to start with how branding and marketing could be used to expand public awareness—separating cardiac arrest from heart diseases overall. Increased public awareness could, in turn, lead to greater advocacy for cardiac arrest and advocacy for additional funding for research. Brown said that, although many people know someone who has experienced a cardiac arrest, most people do not identify cardiac arrest as a top-10 health concern in the United States—signaling a lack of awareness. A few members of Brown's breakout group also considered other fundraising strategies, such as building public-private partnerships with health-oriented funding foundations (e.g., the Bill & Melinda Gates Foundation, the Ford Foundation, Kellogg Foundation) and other partners. Brown and Sanders each offered a list of potential partners that could be engaged to overcome barriers and advance research efforts in the resuscitation field (see Box 3-2).

BOX 3-2
Examples of Potential Partners for Accelerating
Cardiac Arrest Research and Translation

- AARP
- American Heart Association
- American Red Cross
- Centers for Disease Control and Prevention
- Community organizations and rotary clubs
- Food and Drug Administration
- Industry and private-sector organizations
- Media
- National Association of Emergency Medical Services Physicians
- National Institutes of Health
- Patient and disease-specific advocacy organizations
- Patient-Centered Outcomes Research Institute
- Patients and family members
- Payers and insurance companies
- Robert Wood Johnson Foundation
- Sports organizations
- Telecommunication companies (e.g., AT&T, Verizon)

SOURCE: Presented by Jeremy Brown and Arthur Sanders, July 11, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*.

Cardiac arrest could leverage existing resources, infrastructure, and partnerships through a number of existing research programs across the federal government, said Brown. The Centers for Medicare & Medicaid Services' Million Hearts Initiative is just one example. Brown also suggested that the resuscitation field should consider uniting with stroke and trauma to establish an NIH task force. Although improvements are possible using existing resources, true progress will require new and creative strategies, collaboration, and leadership, Brown emphasized, further proposing that the resuscitation field will need to identify a single convener in order to build the public-private partnerships required to stimulate growth across research and translation. It will be important to have a single, collaborative voice as the field moves forward together, concluded Brown.

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Improving Public Awareness and Training

Although the timely use of cardiopulmonary resuscitation (CPR) and automated external defibrillators (AEDs) following a cardiac arrest can improve chances of survival and outcomes, rates of bystander CPR and AED use in the United States are low (less than 3 percent annually) (Anderson et al., 2014; IOM, 2015). A coordinated public education campaign that is implemented at the state and local levels will be necessary to expand public CPR and AED training and improve the provision of bystander CPR and defibrillation (IOM, 2015) (see Box 4-1). As Tom Aufderheide noted during his opening remarks, and Marina Del Rios reiterated, cardiac arrest is not always the last event in a person's life, and if the public is prepared and ready to act, individuals can make a difference and save lives.

CRYSTALLIZING MESSAGING TO PROMOTE PUBLIC AWARENESS

Robert M. Davis, U.S. Department of Homeland Security

In 2003, *USA Today* released an investigative series called *Six Minutes to Live* that was based on 18 months of research conducted by Robert Davis. During his investigation, Davis identified significant geographic disparities in survival rates associated with cardiac arrest and explored the root causes for these variations. The cities with the best survival rates held themselves accountable for outcomes and measured true response

BOX 4-1**Recommendation 2 from*****Strategies to Improve Cardiac Arrest Survival: A Time to Act******Recommendation 2. Foster a Culture of Action Through Public Awareness and Training***

State and local departments of health and education, and leading organizations in cardiac arrest response and treatment, should partner with training organizations, professional organizations, public advocacy groups, community and neighborhood organizations and service providers, and local employers to promote public awareness of the signs, symptoms, and treatment of cardiac arrest. These efforts require public cardiopulmonary resuscitation (CPR) and automated external defibrillator (AED) training across the lifespan, creating a culture of action that prepares and motivates bystanders to respond immediately upon witnessing a cardiac arrest. Specifically,

- state and local education departments should partner with training organizations and public advocacy groups to promote and facilitate CPR and AED training as a graduation requirement for middle and high school students;
- employers (e.g., federal agencies, private business owners, and schools) should be encouraged to maintain easy-to-locate and clearly marked AEDs, provide CPR and AED training to their employees, and specifically include cardiac arrest in formal emergency response plans; and
- local health departments should engage with community and neighborhood organizations and service providers to expand the types and locations of available CPR and AED training to populations over age 65 and caregivers for this population.

SOURCE: IOM, 2015.

times—the continuous time from collapse until the first responder arrived next to the patient and initiated treatment. These cities also measured true survival rates rather than just return of spontaneous circulation. Application of these types of benchmarks, said Davis, allows communities to reflect on the care being provided and determine where improvements should be made.

Beyond reporting on the geographic disparities, the *USA Today* series also included elements of public education. For example, it featured graphics that showed readers exactly how to do CPR and use an AED, encouraging them to act regardless of their level of prior CPR training. Davis emphasized the importance of messaging when educating the public and outlined six key messages about cardiac arrest and resuscitation that should be conveyed (see Box 4-2). Although the media can, and

do, play an essential role in educating the public, the media landscape is shifting. For example, social media are taking precedence, especially with younger audiences, over more traditional mechanisms, such as press conferences and desk-side briefings with medical reporters. The media are strained and stories are being segmented, which can lead to messages being diluted or lost, said Davis. Although mass media can still be used to reach millions of people, they require a lot of time and money. Davis indicated that a comprehensive outreach campaign that includes multi-media, social media, and viral messaging will be needed to effectively increase public awareness and promote bystander action in the face of cardiac arrest.

Unlike other public health campaigns (e.g., seat belts, drunk driving, smoking cessation, cancer screening), scare tactics cannot be used to induce behavior change when it comes to bystander response to cardiac arrest. In other words, said Davis, the message of other campaigns is often “if you do not take action—stop smoking, wear a seat belt, get a mammogram, etc.—you could die.” However, in the case of cardiac arrest, the potential victim is not the audience. The bystanders are the ones who need to be convinced to take action and overcome their fears in order to save someone else’s life. To overcome those fears, outreach efforts could focus on the public’s ability to participate and on how individuals can use their knowledge and skills to save a loved one or stranger who collapses, continued Davis.

Across the resuscitation field, the shared goal is to save lives, said Davis, and partnerships will be vital to success. To realize the goal of reduced mortality, the field could develop, synchronize, and consistently

BOX 4-2
Key Messages for Educating the Public

- A cardiac arrest is not a heart attack.
- Cardiac arrest is a unique health emergency that requires an immediate response.
- Cardiac arrest can be reversed with quick bystander action.
- Bystander resuscitation acts are not difficult, but must be initiated immediately.
- Everyone can learn to identify cardiac arrest and be prepared to save a life.
- Thousands of lives are lost every year due to bystander inaction.

SOURCE: Presented by Robert Davis, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*.

use simple messages, regardless of whether they are applied to educating the public or discussing research funding and results. Davis urged all stakeholders to work together to develop consistent messaging. He said that one of the most powerful stories involves connecting a survivor with his or her rescuer. Whenever possible, these heroic stories need to be discussed publicly and used to promote awareness. Davis noted that the media could also be useful in encouraging accountability across communities and health care systems by reporting on performance and outcomes.

Furthermore, the role of the public should not be underestimated. Increasing public awareness can empower communities to demand accountability and higher standards of care from health care systems and providers. Increased awareness could also result in a larger role for the public in implementing the Institute of Medicine's (IOM's) recommendations. Although not everyone will survive a cardiac arrest, the field has an obligation to engage the public and create an environment of action, concluded Davis.

Complementing Davis's conclusions, Edward Septimus, who spoke later in the workshop (see Chapter 6), noted that the Centers for Disease Control and Prevention has a website called Get Smart that has information and materials geared toward both health care providers and patients. One of the challenges in the context of antimicrobials, said Septimus, has been for health care providers to take the time to educate patients and persuade them that the antibiotic is unnecessary and that monitoring and waiting are appropriate options for certain conditions. Another challenge lies with the financing of these public education campaigns, he said. There are better ways to engage payers and other partners from across the continuum of care in funding joint efforts. There are significant, long-term societal costs associated with inaction, he emphasized. Working together can lead to better outcomes and lower health care costs.

INVESTING IN PATIENT ADVOCACY AND COMMUNITY EDUCATORS TO CHANGE POLICY

Joanne Howes, National Breast Cancer Coalition

A quarter of a century ago, a revitalized women's health movement was under way in the United States and efforts were being made to involve more women in clinical trials and research studies, said Joanne Howes. This movement served, in part, as the impetus for the development of the National Breast Cancer Coalition, which was launched in 1991 with an overarching mission to end breast cancer. At the time, there were hundreds of survivor and advocacy groups across the country that offered

support, education, and care for women with breast cancer. A number of these organizations came together with a desire to change the system and build an effective advocacy coalition. Howes said the coalition was founded on three basic principles: (1) expanding research; (2) improving access to high-quality, evidence-based care; and (3) uniting and fortifying advocacy efforts.

Howes described a number of factors that she believes have contributed to the success of the National Breast Cancer Coalition over the years. For example, the coalition is somewhat unique in that it includes representatives from member organizations that each have a voice and a role to play within the coalition. Furthermore, the coalition's leaders are all trained, volunteer advocates from across the United States who strive to support the coalition and advance its mission. Beyond training for its leadership, the coalition has recognized and understood the value of advocacy training from the beginning. It devised an annual multiday program called Project Lead, which provides survivors and advocates a basic understanding of the relevant science, research methods, statistics, and advocacy strategies before visiting Capitol Hill to meet with congressional leaders and staff. Howes also noted that over the course of its history the coalition has remained dedicated to its mission and only chooses to participate in activities that will ultimately fulfill the mission to end breast cancer.

Since its inception, the coalition has significantly expanded funding for breast cancer research and the role of advocates in research. The coalition's most well-known effort is its partnership with the Department of Defense (DoD) to create the DoD Breast Cancer Research Program, said Howes. As part of this program, advocates from the National Breast Cancer Coalition serve on peer review panels and planning panels, actively interacting with researchers to provide survivor and advocacy perspectives. These advocates question the value and purpose of the research topics being presented and provide guidance to ensure that funding is being directed to studies that will work toward ending breast cancer. Although progress in research has been made, greater investment could help to ensure access to high-quality, evidence-based care, noted Howes. Reiterating a point from previous speakers, Howes said that the field often knows what the current research says to do. However, not all providers keep up with the guidelines and provide care supported by the best available evidence.

In response to an audience question about how to effectively engage the media and large national organizations (e.g., National Football League [NFL], National Basketball Association [NBA], and National Collegiate Athletics Association [NCAA]) to increase awareness about cardiac arrest and the importance of bystander CPR and AED use, Howes noted that

much of the demonstrated goodwill is political. Companies—and corporate America, more broadly—want to create and maintain a good public image. Therefore, they publicly support the fight against breast cancer by branding products with pink and participating in breast cancer awareness activities in October. To start this process for cardiac arrest, the resuscitation field could identify a spokesperson or an organization that can take the lead and represent the field as a whole. Specifically, Howes asked, who will be responsible for approaching the NBA and other organizations about this effort?

Del Rios noted that one of the challenges within the resuscitation field is that many of the organizations work in silos. In response, Howes urged the field and all of its disparate organizations to agree on messaging and strategies to move forward together and begin the necessary outreach work. Howes reiterated that the National Breast Cancer Coalition model could be quite useful to the resuscitation field, noting that a large organization with a big budget is not necessarily required to make sizable changes.

Howes also recommended that public messages be simple, straightforward, and empowering. For example, the message could be “there are actions that individuals can take to save a life, and everyone has a responsibility to know how to do that,” said Howes. Furthermore, a member of the audience highlighted the importance of engaging experts in behavior change, marketing, and advertising when developing messaging for the public to ensure that the messages will be effective. In closing, Howes noted that, while the resuscitation field has many complex challenges to overcome, it should convey a clear message of action to mobilize the public.

PUBLIC AWARENESS AND TRAINING: INNOVATIVE TECHNOLOGIES AS A TOOL TO IMPROVE ACTION

Raina Merchant, University of Pennsylvania

Innovative technologies offer significant promise for improving public awareness and can play a role in communication, marketing, messaging, and connectedness, all themes discussed by previous speakers, noted Raina Merchant. In the resuscitation field, innovative technologies are being developed to improve access to CPR-trained bystanders and AEDs. For example, a recent study evaluated an automated, mobile phone system in Sweden that notifies CPR-trained individuals of possible nearby cardiac arrests that are reported to a local emergency medical services system. These trained bystanders can then use mobile positioning technology to go to a scene and initiate bystander CPR. Although the researchers did

not identify an increase in survival rates, the rates of bystander CPR did increase (Ringh et al., 2015). In the United States, a similar mobile app-based initiative has been developed and is being implemented. The initiative, called PulsePoint, calls on volunteer citizens to respond to possible cardiac arrests and provides information on the location of the nearest AED, when available (Brooks et al., 2016) (see Figure 4-1). In a later presentation, Myron Weisfeldt echoed this point, highlighting PulsePoint as a resuscitation program that could lead to the next major national public policy shift. Merchant indicated that there has been sizable interest in the app, given the ubiquity of mobile phones and the potential to reduce the time from collapse to CPR and defibrillation.

Innovative technologies are also being used to expand access to AEDs. In Philadelphia, researchers developed a mobile app called MyHeartMap and are using crowdsourcing and gamification to engage the public and locate publicly available AEDs in the city. By the end of the contest, the public had reported more than 1,400 AEDs (852 unique entries) (Merchant et al., 2013). The data were made publicly available following the conclusion of the study, and more than 10,000 AEDs have been reported across the state of Pennsylvania since then (Merchant, 2016). Although this app is not connecting bystanders to AEDs when one is needed, said Merchant, just knowing where the AEDs are located is an important first step.

Merchant pointed out that knowing the locations of AEDs is not enough to save a life; the AED must also be noticeable and easily identifiable by a bystander. The Defibrillator Design Challenge used crowdsourcing and asked the public to submit designs that would make AEDs, and their location, stand out and be more memorable. Approximately 119 people submitted designs, such as one that showed Clark Kent open-

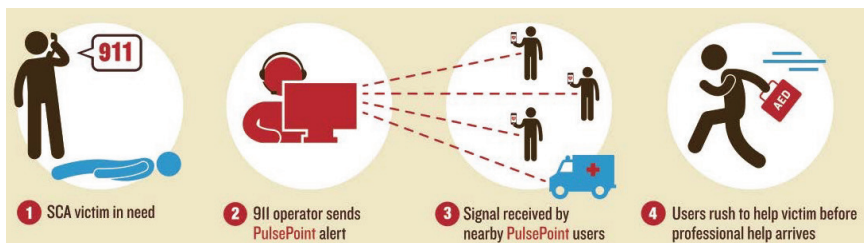


FIGURE 4-1 PulsePoint process.

NOTE: AED = automated external defibrillator; SCA = sudden cardiac arrest.

SOURCE: Presented by Raina Merchant, July 11, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act* (citing PulsePoint, 2016).

ing his shirt to reveal an AED along with his Superman cape, and 2,140 people voted on these entries and provided demographic information (Merchant et al., 2014). Merchant pointed out that the designs offered yet another opportunity for messaging and increased public awareness. Another innovative technology that is being tested to expand access to AEDs is the use of drones for just-in-time AED delivery. Merchant noted that, although this is in the early phases, this approach could reduce the time to defibrillation by eliminating the need to search for and locate an AED.

One workshop participant noted that the NCAA recently released a consensus statement on cardiovascular care for athletes, including cardiac arrest care (Hainline et al., 2016). The participant said a large part of the statement deals with the availability of AEDs and ensuring that colleges and universities are complying with national AED recommendations. Merchant followed up on the participant's comment, saying that just knowing where AEDs are located is not enough. AEDs must be accessible, visible, and functional, and perhaps most importantly, she said, people need to be willing to open the box and use them.

Social media is yet another mechanism that could be used to increase public awareness. Merchant described how researchers have used Twitter to assess public knowledge related to cardiac arrest and to understand how information is shared via tweets (Bosley et al., 2013). In their analysis of tweets, Bosley and colleagues (2013) found that many questions were being posted about cardiac arrest and CPR. The resuscitation field needs to determine how to use messaging effectively to answer the public's questions and to better educate individuals about cardiac arrest symptoms and treatment, said Merchant. In considering how the resuscitation field and researchers can harness the billions of bits of data available through social media and crowdsourcing along with the public enthusiasm, Merchant pointed out that the American Heart Association recently released a scientific statement titled *Use of Mobile Devices, Social Media, and Crowdsourcing as Digital Strategies to Improve Emergency Cardiovascular Care* (Rumsfeld et al., 2016). The statement outlines potential research questions to guide further investigations related to the use of these tools to improve the timely response and treatment of cardiovascular emergencies, including cardiac arrest. Merchant noted that this statement could be used as a starting point for progress in adopting innovative technologies to improve public awareness and response to cardiac arrest.

In response to a question about the state of the science for using cell phones to instruct people in hands-only CPR techniques, Merchant said there are several good apps available that provide instruction and sometimes a metronome to assist with compression rates. For people who have taken CPR training, the apps serve as a great refresher. Merchant said a

number of studies have also demonstrated that these apps can provide increased confidence in doing CPR—a serious barrier for many individuals. Despite the widespread availability of these apps, the uptake rates are not as high as they could be, representing an opportunity for the resuscitation field. However, determining how to encourage the public to download and regularly use the training apps is a challenge, said Merchant.

BREAKOUT SESSION REPORT: ESTABLISHING A PUBLIC AWARENESS CAMPAIGN

Paul Pepe, Planning Committee Member¹

Paul Pepe moderated the breakout session on strategies to establish a public awareness campaign and advance the second recommendation from the IOM's report (see Appendix A). In his opening remarks, Pepe noted that increasing public awareness is an intermediate step for achieving the overarching goal of creating a culture of action in which bystanders are prepared and motivated to immediately respond to a cardiac arrest and save a life.

As described in the IOM's report, a number of barriers impede action from the public. For example, individual participants in the group identified barriers such as the public not recognizing cardiac arrest as a major public health concern, fear of injuring someone when doing CPR or using an AED, and a lack of confidence in skills and training. To overcome these barriers, individual breakout group participants brainstormed a number of possible strategies to consider when developing messaging:

- Use a singular, simple, concise, easy-to-communicate, and compelling message. Participants identified some examples to follow, including “Only you can prevent wildfires” and “Stop, drop, and roll.”
- Emphasize that individuals can save a life *today*, that training is simple and easy, and that CPR and AEDs are safe and effective tools that anyone can use.
- Help the public differentiate between cardiac arrest and a heart attack, and underscore that all loved ones are at risk.

¹ Breakout session presenters were asked to summarize the major ideas and opinions proposed by individual participants during their respective breakout sessions. Individual statements described below are not necessarily the position of the presenter and should not be interpreted as consensus statements from the breakout group as a whole or of the National Academies of Sciences, Engineering, and Medicine.

- Remind people that the majority of cardiac arrests occur in homes and offices. Therefore, everyone needs to be ready to act.

Pepe urged the field to engage professional communication experts and focus groups, come to a consensus, and use the agreed-upon messaging consistently. Conveying the persuasive messages and motivating action will likely require a multifaceted outreach strategy, said Pepe. He noted that, although a mass media campaign could reach a large audience, resource limitations may be a challenge and sustainability is not guaranteed. Social media offer a lot of potential. However, Pepe said that marketing experts should carefully plan outreach through these channels, and more broadly, ensure the use of fully tested and validated messages that reach all audiences, including vulnerable populations.

Effective outreach will also necessitate collaboration across a range of stakeholder groups in a variety of settings, said Pepe. For example, some individuals in the breakout groups noted that health care providers and health care settings could play a role in public education efforts. For example, pediatricians could ask parents about CPR training, and posters in waiting rooms could be used to show how to identify cardiac arrest and what to do. Furthermore, schools, employers, businesses, community groups (e.g., faith-based organizations, youth groups), and advocacy organizations (e.g., AARP) should be engaged as valuable local partners, said Pepe. The resuscitation field should also consider developing a network or uniting and fortifying existing groups that include survivors, individuals who have lost a loved one to cardiac arrest, and patient advocates who can be called on to share their powerful stories, some breakout group members suggested. Whenever possible, these individuals should receive advocacy training and be actively involved in outreach initiatives, although outreach endeavors may be resource intensive, Pepe said.

**BREAKOUT SESSION REPORT:
FOSTERING A CULTURE OF ACTION IN
COMMUNITIES THROUGH POLICY**

Marina Del Rios, Planning Committee Member²

Marina Del Rios moderated the breakout session that focused on fostering a culture of action in communities through policy. Similar to the breakout session led by Pepe, the discussion from this session was also

² Breakout session presenters were asked to summarize the major ideas and opinions proposed by individual participants during their respective breakout sessions. Individual statements described below are not necessarily the position of the presenter and should

BOX 4-3
Potential Partners for Fostering Cultural Change

- Federal Government Agencies: Department of Education, Food and Drug Administration, Health Resources and Services Administration, and Occupational Safety and Health Administration
- State and Local Government Entities: health departments, school systems, and others
- National Organizations: AARP, American Camp Association, American Heart Association, American Hospital Association, American Public Health Association, American Red Cross, Hypertrophic Cardiomyopathy Association, Louis J. Acompora Memorial Foundation, National Association of School Nurses, National Business
- Coalition on Health, National Fire Protection Association, National Parent Teacher Association (PTA), Parent Heart Watch, Sudden Cardiac Arrest Foundation, cardiac arrest survivor networks, among many others
- State and Local Organizations: state emergency medical services and ambulance associations, local school boards, teachers' associations, local PTAs, local chambers of commerce, local fire chiefs, fire fighter associations, faith-based community organizations, Boys & Girls Clubs, among many others

SOURCE: Presented by Marina Del Rios, July 11, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*.

linked to the second recommendation from the IOM's report. In its discussion, this group considered potential partners, barriers to creating cultural changes, and policy changes at the national, state, and local levels. The individual breakout group participants identified a plethora of possible public and private organizations that could be involved in community-based action initiatives (see Box 4-3). Del Rios noted that the resuscitation field could look to successful state lobbying coalitions for lessons related to developing partnerships and implementing policy change. The group also discussed partnering with existing state and national networks that are dedicated to other time-sensitive health conditions, said Del Rios. For example, stroke, trauma, and acute myocardial infarction offer potential partnerships. Whenever possible, the cultural changes need to be driven from a grassroots level, said Del Rios. Additionally, some breakout group members suggested that community-centered initiatives to improve

not be interpreted as consensus statements from the breakout group as a whole or of the National Academies of Sciences, Engineering, and Medicine.

response to cardiac arrest should include factors related to motivation, ability, influence of others, and influence of physical surroundings.

This breakout group discussed numerous barriers to establishing a culture of action in communities across the United States. The primary barriers that Del Rios highlighted included the following:

- As discussed in previous breakout and plenary sessions, the lack of unified messaging creates a mixed media narrative and potential confusion among the public, especially in the context of how to recognize and respond to cardiac arrest versus heart attack.
- There is a lack of local, state, and national mandates for accessible, visible AEDs located near the entrance of public buildings.
- Good Samaritan laws are inadequate and the public has misperceptions about what those laws entail. Del Rios said there needs to be a national template that can be used to promote legislative consistency across states.
- There is a lack of an organized, independent, and active national survivors and family network (including family and friends of non-survivors) with strong leadership that can serve as a voice for cardiac arrest on the national level. Del Rios noted that current survivor organizations are disjointed and primarily operate at local and state levels.
- The public has misperceptions about the complexity and length of CPR and AED training.
- Psychological barriers prevent certain individuals, some of whom have had CPR training, from helping when confronted with a cardiac arrest. Del Rios said that inaction following a cardiac arrest needs to become socially unacceptable.

When asked about possible barriers to requiring CPR and AED training as a high school graduation requirement, Del Rios said that school systems and teacher associations have voiced concerns about unfunded mandates and having to restructure curricula that are already strained by time limitations. The potential costs of developing and maintaining a CPR and AED training program are particularly problematic for low-income schools. However, one workshop participant pointed out that there are organizations that can provide free mannequins and support for these programs. Therefore, building sustainable, low-cost programs is a possibility, said the participant, if this is defined as a policy priority at state and local levels. Del Rios also noted that the Department of Education could be asked to develop guidance on school-based CPR programs and possibly provide funding to support these programs.

In considering opportunities to expand access to bystander CPR and

AED use, the group highlighted policy changes at the national, state, and local levels that could have an impact. At the national level, some participants in the group suggested that the Food and Drug Administration consider updating its AED regulations to require that all new AEDs include a standardized geolocation technology, making AEDs easier to locate and increasing public access. At the state and local levels, Del Rios said that dispatcher-assisted CPR should be required. This type of policy change could significantly increase the availability of bystander CPR. Furthermore, leveraging existing state and local policies, such as fire alarm testing and building inspections, could be useful in ensuring that AEDs are available, prominently displayed, and functional. Del Rios also noted that hospitals and health care systems could include CPR training as part of their community health needs assessments to identify areas for improvement and develop strategies to fill training gaps.

BREAKOUT SESSION REPORT: INNOVATIVE TECHNOLOGIES AS A PUBLIC HEALTH TOOL

Raina Merchant, Planning Committee Member³

Raina Merchant facilitated the breakout session on how innovative technologies can be used as public health tools. Merchant first noted that technology is not a replacement for current tools, but rather a mechanism to better integrate and optimize existing systems. During the breakout session, the group discussed the possible benefits and detriments of several technologies that could be broadly implemented for three primary purposes: data collection and research, training and prompting (e.g., guided CPR), and connecting individuals with necessary resources. Some members of the group identified privacy as a unifying challenge relevant to each of the technologies discussed during the session.

First, the group considered the potential of mobile technologies, such as cell phones, to help overcome public inaction. As discussed previously, there are many benefits associated with mobile technology—for example high per-capita cell phone ownership, geolocation and navigation features for locating AEDs and potential rescuers, and availability of just-in-time instruction. However, there are also challenges associated with fully integrating cell phones into 911 processes. Merchant pointed out that many

³ Breakout session presenters were asked to summarize the major ideas and opinions proposed by individual participants during their respective breakout sessions. Individual statements described below are not necessarily the position of the presenter and should not be interpreted as consensus statements from the breakout group as a whole or of the National Academies of Sciences, Engineering, and Medicine.

911 localities are unable to accept or send text messages, limiting communication opportunities. Some members of the breakout group identified 911 improvements as low-hanging fruit, indicating that the capability to send and receive text messages, images, and videos combined with the use of built-in geolocation technologies could greatly expand information transfer possibilities and promote further public response to cardiac arrests. As with other applications of mobile technologies, privacy concerns would be applicable. There are also questions regarding the limitations of the technologies and the quality of the data provided, such as the accuracy of geolocation in high-rise buildings.

Merchant described sensors and wearable technologies as opportunities to harness the data that these devices collect to identify cardiac arrests in real time and alert rescuers. Although early detection is a significant benefit, the value of these devices is currently limited given the modest adoption rates among the public, she stated. Additional studies would be required to assess the quality and accuracy of the data from these devices and manage potential privacy concerns. In thinking about the development of new technologies and apps, the group discussed the use of hack-a-thons, gamification, and innovation challenges. These types of initiatives often include varying levels of prize money and may call for the participation of interdisciplinary teams in order to inspire the generation of new ideas, unconventional designs, and creative solutions to existing problems. For example, Merchant said the resuscitation field could convene a hack-a-thon to optimize app-based CPR instruction. The challenges with these approaches include additional testing requirements, assurance that the ideas produced are indeed novel and better than existing options, and determining which products will be implemented broadly, some individuals noted.

The breakout group also considered the intersection between technology and public engagement and training. Many technologies are available that could be leveraged to increase public awareness, involvement, and training, said Merchant. Social media, videos, games, apps, and simulation were discussed as possibilities, especially as mechanisms to reach younger audiences. One workshop participant asked Merchant about the potential for using social media and other technologies to study cardiac arrest risk factors. Merchant noted that the data available through social media and mobile technologies, including sensors and wearable technologies, offer incredible research potential to explore complex questions, such as risk for cardiac arrest. The possibility of two-way communication with social media also opens up new educational opportunities to share accurate messages about cardiac arrest, CPR, and AEDs, thus enhancing public communication and connectedness. Although the promise of new technologies can be appealing, developing, testing, and implementing

these technologies can require large investments and time-consuming research, Merchant commented. On the other hand, optimizing existing low-tech tools could offer equal or greater returns. For example, removing signs on AEDs indicating that only trained professionals should use them or educating the public about hands-only CPR guidelines could remove barriers to public action and response to cardiac arrest.

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Enhancing the Emergency Medical Services Response to Cardiac Arrest

Emergency medical services (EMS) systems across the United States provide professional prehospital cardiac arrest care and are essential to the efficacy of the chain of survival (see Chapter 1). EMS systems are operated primarily on a local level and include a range of trained personnel, including 911 dispatchers, emergency medical technicians (EMTs), and paramedics. Despite fragmented oversight and variations in structure and operations, exemplar EMS systems have implemented data collection systems and performance improvement initiatives that have led to sizable increases in survival rates for out-of-hospital cardiac arrest (OHCA) (IOM, 2015). These advances offer the potential to reduce gaps in performance and outcomes through broader adoption of evidence-based best practices nationwide. Recommendations 3 and 5 from the Institute of Medicine's (IOM's) report describe opportunities for strengthening the capabilities and performance across EMS systems, while implementing continuous quality improvement programs (see Box 5-1).

CARDIAC ARREST AS A POLICY PRIORITY

Myron Weisfeldt, Johns Hopkins University

Since the development of cardiopulmonary resuscitation (CPR) nearly 60 years ago, a number of public policy changes have been adopted in order to expand access to CPR treatments and increase survival rates for out-of-hospital cardiac arrest (see Box 5-2), began Myron Weisfeldt. Each of these policy changes shared a set of similar characteristics that

BOX 5-1**Recommendations 3 and 5 from
*Strategies to Improve Cardiac Arrest Survival: A Time to Act*****Recommendation 3. *Enhance the Capabilities and Performance of Emergency Medical Services (EMS) Systems***

As the informal agency for EMS, the National Highway Traffic Safety Administration should coordinate with other federal agencies and representatives from private industry, states, professional organizations, first responders, EMS systems, and nonprofit organizations to promote uniformly high-quality emergency medical systems by

- convening interested stakeholders to develop standardized dispatcher-assisted cardiopulmonary resuscitation (CPR) protocols and national educational standards for use by all public safety answering points; and
- establishing a standardized definition and training curriculum for high-performance CPR to be used in basic emergency medical technician training and certification.

Recommendation 5. *Adopt Continuous Quality Improvement Programs*
Emergency medical services (EMS) systems, health care systems, and hospitals should adopt formal, continuous quality improvement programs for cardiac arrest response that

- assign responsibility, authority, and accountability within each organization or agency for specific cardiac arrest measures;
- implement core technical and non-technical training, simulation, and debriefing protocols to ensure that EMS and hospital personnel can respond competently to both adult and pediatric cardiac arrests; and
- actively collaborate and share data to facilitate national, state, and local benchmarking for quality improvement.

SOURCE: IOM, 2015.

contributed to their adoption and success. First, all of the policy changes were singular, notable events. Second, they were supported by solid, scientific evidence. Third, they captured the public's imagination and interest. Finally, they gained multiple endorsements before becoming informed public policy.

Weisfeldt cited two promising examples of activities that could develop into major public policies to advance resuscitation science and survival in the United States. The first initiative uses technology to link layperson responders to people who suffer an arrest and automated external defibrillators (AEDs). Citing an earlier presentation by Raina

BOX 5-2
Examples of the Evolution in Resuscitation Policy

- **1967:** The National Research Council endorsed training the public in cardiopulmonary resuscitation (CPR) techniques. Following this endorsement, the American Heart Association and the American Red Cross took the lead in CPR training for the public (NRC, 1967).
- **1968–1970:** The definition of “first responder” was expanded to include fire fighters. This change resulted in widespread CPR training for firefighters and equipped fire response vehicles with automated external defibrillators (AEDs) (Eisenberg, 2013).
- **1998–2004:** The American Heart Association began advocating for public access to AEDs. As a result of these efforts, lawmakers in every state passed legislation to include defibrillation under existing Good Samaritan laws. In 2004, the National Heart, Lung, and Blood Institute released findings from the Public Access Defibrillation Trials, which demonstrated that public access to AEDs did have a positive impact on survival rates (The Public Access Defibrillation Trial Investigators, 2004).
- **2008:** The American Heart Association updated its CPR guidelines to focus on hands-only CPR training for the public, eliminating guidance for bystander mouth-to-mouth ventilation (Sayre et al., 2008).
- **2010–present:** An expanded role for 911 dispatchers is being developed to coach callers through CPR procedures, regardless of prior training or experience, until first responders arrive and can assume resuscitation responsibilities (Bobrow et al., 2014; Lewis et al., 2013; Song et al., 2014).

SOURCE: Presented by Myron Weisfeldt, July 12, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*.

Merchant (see Chapter 4), Weisfeldt pointed to the PulsePoint program, which is being piloted in Los Angeles and Seattle. The program uses cell phone technology to map AEDs in public spaces. It also alerts bystanders trained in CPR and AED use to the location of potential cardiac arrest patients, following a 911 call.

The second initiative trains police officers as first responders for cardiac arrest and equips every police vehicle with an AED. In a preliminary study conducted in the Netherlands between 2006 and 2012, researchers found that AED use nearly tripled during the study (21 percent to 59 percent). The overall increase was attributed to rises in rates of both public use of stationary, onsite AEDs (from 6 to 11 percent) and police use of mobile AEDs (from 16 to 49 percent) (Blom et al., 2014). Over the course of the study, researchers also observed an increase in survival rates with

positive neurological outcomes—from 16 to 20 percent overall. More specifically, survival rates for cardiac arrests exhibiting shockable rhythms increased from 29 to 41 percent (Blom et al., 2014).

Weisfeldt concluded by underscoring the potential of these initiatives to have a lasting impact on cardiac arrest survival rates if adopted into broader public health policies. The initiatives are singular, evidence-based advances that can spark public engagement and interest. All that is needed is the endorsement of important stakeholders to fuel implementation at the national level.

DISPATCHER-ASSISTED CPR¹: CURRENT PROGRESS AND EMERGING TECHNOLOGIES

Drew Dawson, National Highway Traffic Safety Administration (retired)

Dispatcher-assisted CPR increases rates of bystander CPR, decreases the time between collapse and preliminary chest compression, and if done correctly, emphasized Drew Dawson, increases survival rates following cardiac arrest. Dispatcher-assisted CPR programs can provide significant return on investment when they are set up within established EMS systems. Dawson noted that training dispatchers to provide CPR instruction has a multiplier effect when compared with bystander CPR training. For example, CPR-trained bystanders may witness only one cardiac arrest in their lifetime. However, when dispatchers are trained to provide CPR instruction over the phone, they are able to coach numerous bystanders in CPR techniques, thus expanding the reach and value of their training.

Effective dispatcher-assisted CPR programs require dispatchers to be confident and proficient in rapidly identifying cardiac arrest, convincing bystanders to begin chest compressions—ideally within 120 seconds—and conveying clear, assertive CPR instruction, said Dawson. At the systems level, successful programs require commitment and a supportive culture across the EMS system and the public safety answering point (PSAP). In order to establish accountability and continually improve, mechanisms to measure and report performance benchmarks need to be an integral part of the program, stated Dawson. Despite the possible benefits and the relatively small investment required, only about half of PSAPs in the United States provide dispatcher-assisted CPR. Of those PSAPs that do offer dispatcher-assisted CPR, most do not measure or report their performance. Dawson stressed that “delivering instructions late or poorly is like not delivering them at all.” On the national level, performance standards

¹ Dispatcher-assisted CPR is also referred to as dispatcher-assisted bystander CPR, just-in-time instruction, telecommunicator CPR, and telephone CPR.

for dispatcher-assisted CPR do not exist. Dawson observed a frequent lack of awareness and enthusiasm, and he hypothesized that most health care systems do not recognize the potential return on investment that these programs offer.

From a technical perspective, continued research is essential to augment dispatcher-assisted CPR processes and techniques, said Dawson. New studies could be used to devise and test strategies to help dispatchers quickly identify cardiac arrest over the phone and persuade callers to perform CPR without hesitation. As PSAPs transition to the next generation of 911 technologies, dispatchers will have greater flexibility to seamlessly transfer calls, which could be useful in developing a more regionalized approach to dispatcher-assisted CPR. Although every emergency call should have access to guideline-based CPR instruction, said Dawson, not every PSAP needs to actually provide the CPR instruction. Applying this model, 911 calls that require CPR instruction could be quickly transferred to a regional center equipped to provide high-quality, dispatcher-assisted CPR. Regional centers and PSAPs that comply with standards and maintain high performance could be awarded a special designation, such as 911 center of life-saving excellence, suggested Dawson.

Within the EMS and dispatcher community, a variety of organizations are engaged in standard-setting initiatives (e.g., National Emergency Number Association, National Fire Protection Association, Association of Public-Safety Communications Officials, ASTM International) that could help promote the benefits of dispatcher-assisted CPR. Dawson called on these organizations and the American Heart Association to develop and endorse national dispatcher-assisted CPR standards. Stronger partnerships at the state level among state EMS offices, state health agencies, state 911 offices, and health care systems are also needed to bolster certification requirements, increase awareness, and expand implementation, he said. To advance dispatcher-assisted CPR in the United States, Dawson suggested that the National Highway Traffic Safety Administration (NHTSA) convene a national summit on dispatcher-assisted CPR. The summit could involve key decision makers from across the country and should culminate with the development of a coherent national action plan with commitments from agencies and organizations to implement that plan. Dawson emphasized that dispatcher-assisted CPR should be a national priority and that there should be a national expectation that CPR instruction will be readily available for every single cardiac arrest call that comes through a PSAP.

In response to a participant's question about the possibility of implementing an automated dispatcher-CPR system to reduce variation in performance, Dawson pointed out that the interaction between the caller and dispatcher is often a critical element of successful bystander CPR.

He noted that part of that interaction is the dispatcher being able to calm down the caller, listen to what is happening at the scene, hear what is going on with the patient, and determine how all of these aspects should be factored into the instructions given to the caller. One workshop participant, who had performed dispatcher-assisted CPR and saved her husband's life, noted that the human connection with the dispatcher is what gave her the strength to do CPR. The participant said she and the dispatcher worked as a team that day while waiting for the ambulance to arrive and take over her husband's care.

Dawson also noted that regionalizing dispatcher-assisted CPR would have greater advantages over automating the system. For example, a regionalized system would ensure that trained dispatchers, who have experience providing CPR instruction to callers regularly, are the personnel providing support to callers. This approach would reduce the need to train all dispatchers and would allow some dispatchers to become highly proficient, said Dawson.

Although there are technological challenges associated with improving 911, most of the gaps are a result of communication and relationship barriers, Dawson said in response to a participant who noted a disconnect between some local law enforcement agencies and EMS medical directors and personnel regarding PSAPs. Both Dawson and Arthur Kellermann reiterated that strong partnerships at the local level are required to improve 911 systems and cardiac arrest care, regardless of who operates the PSAP (e.g., law enforcement, fire, EMS). Dawson indicated that the relevant stakeholders need to build these relationships and work together to develop and review protocols relevant to cardiac arrest care. Peter Taillac, another panelist, noted that the disconnect could also be resolved through regionalization if the law enforcement agency that operates the PSAP could transfer medical calls to a regional call center staffed by dispatchers who are trained to provide high-quality instruction before arrival.

ACHIEVING STANDARDIZATION AND ADOPTION OF HIGH-QUALITY CPR PERFORMANCE ACROSS THE COUNTRY

Arthur Kellermann, Uniformed Services University of the Health Sciences

Prior to organizational changes in 2015, the IOM publications included a quote from Goethe, "Knowing is not enough; we must apply. Willing is not enough; we must do."² In the context of OHCA, Arthur Kellermann

² Beginning in July 2015, the consensus studies and convening activities of the Institute of Medicine were integrated into the work of the National Academies of Sciences, Engineering,

asked, what is already known about strategies to increase survival rates? A meta-analysis conducted by Sasson and colleagues (2010) identified four main factors that are associated with increased rates of survival, including whether

- the collapse is witnessed by a bystander or EMS personnel;
- the individual receives bystander CPR;
- the rhythm can be shocked; or
- return of spontaneous circulation is achieved at the scene.

We know what needs to be done to improve survival rates for OHCA, said Kellermann. Rates of bystander CPR should be optimized, defibrillators should be applied as quickly as possible, and efforts should be focused on resuscitating the patient at the scene. But despite all the resources expended on OHCA research, training, and equipment, Sasson and colleagues (2010) found that survival rates for OHCA remained flat between 1980 and 2008 at just 7.6 percent. Kellermann emphasized that this is not a failure of knowledge, but rather a failure to consistently apply what we know.

The Cardiac Arrest Registry to Enhance Survival (CARES) was created with support from the Centers for Disease Control and Prevention more than a decade ago and, as of the workshop, included 17 state-based registries and approximately 50 large communities, covering nearly 90 million Americans (CARES, 2016; see also Chapter 2). The registry collects outcomes data, measures critical performance parameters, and allows health care systems and communities to compare their performance to similarly situated systems and communities. CARES data have demonstrated that survival rates vary significantly from one city to another—ranging from 5 to more than 50 percent (Kellermann, 2016). This 10-fold difference cannot be explained by genetics or city-to-city variation in comorbidities (e.g., hypertension) or lifestyle (e.g., high-fat diets), said Kellermann. This variation in outcomes reflects wide disparities in the quality of prehospital care. The registry costs less than \$100 million per year or about one penny per individual—it is quite cost-effective, said Kellermann.

Many communities that joined CARES have subsequently improved their OHCA survival rates. Kellermann suggested this may be due to the Hawthorne effect, which means that performance typically improves when it is observed and measured. “When we know how we stack up compared to others, we raise our game,” said Kellermann. In his opinion,

and Medicine (the National Academies), and the program unit that carries out these activities is now called the Health and Medicine Division.

BOX 5-3**A Suggested Revitalization of the ABCs of Cardiac Arrest**

- **A = Accountability**
Every community should participate in a cardiac arrest registry.
- **B = Bystander cardiopulmonary resuscitation (CPR)**
Every community should demonstrate a 60–80 percent rate of bystander CPR, not 15–20 percent.
- **C = Cardiocerebral resuscitation**
This is an optimal resuscitation approach used by advanced life support personnel to minimize unnecessary ventilation, maximize compression density, and increase chances of survival.

SOURCE: Presented by Arthur Kellermann, July 12, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act* (citing Kellermann, 2010).

Kellermann believes that all communities should participate in an OHCA registry that benchmarks performance around key measures associated with the chain of survival. In the past, the “ABCs” of cardiac arrest stood for (A)irway, (B)reathing, and (C)irculation, said Kellermann. More recent research indicates that this is not the optimal sequence of response, with the first priority being placed on chest compressions to restore some degree of circulation. Kellermann urged that the ABCs be redefined for the modern era to emphasize what communities should do to improve their approach to treating OHCA (see Box 5-3).

At the community level, an increase in rates of bystander CPR is possible through a variety of strategies. As described previously by Dawson, dispatcher-assisted CPR is an effective way to increase bystander CPR rates within communities. Video self-instruction and mobile technologies are also expanding training opportunities for individuals and may be more effective than a sponsored 4-hour course, said Kellermann. Merchant and colleagues (2010) found that providing audio instruction via cell phones can also help bystanders to perform better CPR, regardless of prior CPR training experience (see also Chapter 4). In terms of improving the quality of CPR administered by health care providers, Bobrow and colleagues (2008) demonstrated that minimal interruptions during chest compressions can result in increased chances of survival. Kellermann reflected on his experiences performing CPR in the emergency room and said interruptions occurred on numerous occasions for many reasons, and those interruptions were almost certainly detrimental to the patients he treated.

In response to an audience question, Kellermann hypothesized that cardiac arrest survival rates across the United States could be doubled or tripled within 24 months if a concerted national effort were made to improve a few simple processes. These include a relentless focus on boosting rates of bystander CPR, ensuring optimal EMS performance, and promoting universal accountability with a national OHCA registry, emphasized Kellermann. Additionally, the resuscitation field needs to generate public confidence and excitement to support a research agenda that will lead to further progress. This is an attainable goal. “We know we can do better,” said Kellermann, as he called for action.

PROMOTING QUALITY IMPROVEMENT PROCESSES IN EMS SYSTEMS

Peter Taillac, National Association of State EMS Officials

The United States has more than 21,000 licensed EMS agencies (NHTSA, 2011). Because each of these agencies was established to meet the respective needs of communities across the country, there is great variety in the structure, budgets, and operational policies and protocols that are used to manage these agencies. Nationwide, EMS agencies cover the complete spectrum—from large urban systems associated with medical centers that include professional paid personnel to tiny rural agencies that are managed completely by trained volunteers. Coordinating these agencies and ensuring that best practices are implemented consistently is a complex undertaking. Historically there have been few national standards to guide and coordinate the provision of emergency care, noted Taillac. However, the IOM’s report *Emergency Medical Services: At the Crossroads* (IOM, 2006) established a strategic template that EMS leaders have since championed. Through their efforts over the past decade, EMS leaders and organizations have developed a range of national EMS standards and guidelines that are now available to promote the development of coherent protocols and emergency care across all agencies (see Box 5-4).

Taillac observed that another valuable step forward since the release of the IOM report in 2006 occurred in 2010 when the American Board of Medical Specialties authorized a subspecialty certification in EMS under the auspices of the American Board of Emergency Medicine. The recognition of EMS as a subspecialty allows physicians who are interested in EMS to complete a fellowship, gain board certification, and become experts and leaders in the field and in their communities. Across the EMS community, there has also been a greater emphasis on research in the past decade, said Taillac. Medical directors and paramedics in the field are working

BOX 5-4
National EMS Standards and Guidelines

- **National Highway Traffic Safety Administration's Office of Emergency Medical Services (EMS):** National Scope of Practice document (NHTSA, 2007)
- **Health Resources and Services Administration:** Pediatric EMS Standards
- **National Association of State EMS Officials:** National Model EMS Clinical Guidelines (NASEMSO Medical Directors Council, 2014)
- **National Registry of Emergency Medical Technicians:** National emergency medical technician (EMT) certification standards (NREMT, n.d.)
- **Committee on Accreditation of EMS Programs:** National paramedic training standards and certifications (CoAEMSP, 2016)

SOURCE: Presented by Peter Taillac, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*.

to generate a research foundation on which evidence-based practices and guidelines can be built.

At a national level, measuring performance and outcomes can help determine whether EMS agencies are following available guidelines and whether the implementation of those guidelines is leading to better outcomes, said Taillac. NHTSA and the National Association of State EMS Officials are currently developing EMS performance measures for cardiac arrest, trauma, and ST-elevation myocardial infarction (STEMI) through the EMS Compass program. Now in the testing phase, the cardiac arrest measures include rates of bystander CPR, rates of dispatcher-assisted CPR, time from 911 call to first compressions, time to defibrillation, average rate and depth of compression, among others. During this phase, vendors are integrating some of these measures into the electronic patient care record systems in order to increase awareness across individual EMS personnel and agencies. In addition to these efforts, Taillac also suggested that organizations that develop evidence-based guidelines should include corresponding performance measures. If there is guidance on a given treatment or technique, said Taillac, there should be a way to measure that it is being done correctly and making a difference in care.

Now that standards and guidelines are being put in place and a new focus on research has been kindled, Taillac called for incremental moves toward a culture of excellence through performance improvement within all EMS agencies. To establish a culture of excellence, EMS agencies need more feedback, noted Taillac. Performance needs to be linked to outcomes

for EMS personnel, and they need to receive the data to be fully invested, he added. For example, EMS personnel should know the rates of survival to discharge for their patients and how those rates shift from one year to the next. Regardless of whether it is the Hawthorne effect or the inherently competitive nature of paramedics and EMTs that underlies change at the local level, “if we don’t measure [performance], we can’t improve,” emphasized Taillac.

In terms of challenges, Taillac highlighted education and incentives as the two primary challenges. First, state and local EMS agencies and personnel need to understand what performance improvement is, why it is important, and how to use it to improve outcomes. This will require education, stated Taillac. Incentives will be necessary to realize the full potential of performance improvement, and this comes down to resources—funding and time—said Taillac. Many of these agencies have limited resources and may view additional requirements as unfunded mandates. However, Taillac pointed out that the provision of high-quality patient care, including performance improvement, should not be considered an unfunded mandate. Although state-level officials could require some form of performance improvement program as part of a licensing requirement, Taillac believes the incentives should be positive rather than punitive.

In response to a question about the appropriate balance between publicly available data and private EMS data, Taillac noted that most of the EMS registries (e.g., CARES) are voluntary. He believes that if the data were publicly available and posted on a website, EMS agencies and hospitals would be much less inclined to participate. At this early juncture, said Taillac, it makes sense to provide EMS agencies with their own data and comparison data. This approach provides motivation to improve, and when outcomes do improve, the agencies can release the data and advertise their achievements. “I see the argument for the public having access to all of these data,” said Taillac, “but I think you have to be careful. It could become counterproductive, especially early on in these efforts.”

One workshop participant endorsed making data available internally to EMS personnel. In the participant’s health care system, outcomes related to STEMI are posted in the emergency departments within 24 hours to recognize the achievements of specific EMS teams, which also stokes competition to improve. The hospitals and EMS agencies within this system have moved regional EMS meetings into the hospitals, where EMS personnel and physicians review the data and discuss cases in terms of what went well and what could be done better next time. Paul Pepe reiterated that the systems need to collect and review the data or they cannot improve, and it often takes a strong, committed medical director to guide change. Another workshop participant reported that the EMS

agencies in Palm Beach County, Florida, were able to double cardiac arrest survival rates in 3 months because of the dedication of the EMS medical directors and personnel in the county.

BREAKOUT SESSION REPORT: DISPATCHER-ASSISTED CPR

Paul Pepe, Planning Committee Member³

Paul Pepe facilitated a breakout session focused on enhancing and expanding the use of dispatcher-assisted CPR across the United States in response to the third recommendation in the IOM's report (see Appendix A). Pepe noted that only about half of 911 PSAPs in the United States formally use emergency medical dispatchers, who can provide pre-EMS arrival instructions (PAIs). This represents a fundamental challenge to expanding dispatcher-assisted CPR, remarked Pepe.

The participants from this breakout session contemplated regionalization of dispatcher-assisted CPR tasks. Pepe said the adoption of new technologies (e.g., smart phone communication apps, geolocation technologies) holds significant potential for enhancing dispatcher-assisted CPR. For example, cell phone video capabilities could give dispatchers a much better understanding of the scene and even the patient's condition. This could expedite recognition of the need for PAI and even improve the quality of CPR by giving enhanced guidance to callers, explained Pepe. Additionally, the availability of an up-to-date AED registry or database that documents AED locations, especially in highly trafficked public areas, could allow dispatchers to routinely instruct callers where to find the nearest AED, noted some members of the breakout session.

Enhancing dispatcher-assisted CPR procedures may require constant monitoring and reevaluation of the PAIs used by dispatchers, said Pepe. This includes review and feedback to the emergency medical departments, as well as implementation of emerging technologies coupled with research efforts, said Pepe. Some individuals identified a need to develop an inventory of available protocols, best practices, and lessons learned across the United States and to review the availability and effectiveness of dispatcher procedures, especially as they affect underserved communities, such as language and cultural barriers. Although standardization of

³ Breakout session presenters were asked to summarize the major ideas and opinions proposed by individual participants during their respective breakout sessions. Individual statements described below are not necessarily the position of the presenter and should not be interpreted as consensus statements from the breakout group as a whole or of the National Academies of Sciences, Engineering, and Medicine.

CPR protocols nationwide theoretically could be beneficial, especially if they drive quality improvements, Pepe emphasized flexibility to account for local needs and the testing of innovative practices—standardized protocols should not stifle inventive thinking or limit modifications that enhance local needs.

Deviating from standardized protocols should be documented, tested, and reported to strengthen the evidence base for changes in practice and guidelines, said Pepe. He cited the successful *No-No-Go* protocol that was designed to promote prearrival instructions. In cities where this simplified protocol has been deployed, dispatchers ask callers if the individual is awake (or can be wakened) and if the individual is “breathing normally.” If the answer to both of those questions is no (no-no), then the dispatcher initiates CPR instruction (go). This can reduce the time from collapse to first compressions, Pepe stated.

Education and quality assurance (QA) reviews, either in real time or by assessing taped files, are key to improving the quality of dispatcher-assisted CPR, said Pepe. Such reviews should involve constructive feedback that can lead to procedural modifications, said Pepe. As part of both regular group training and individual QA review, dispatchers could receive feedback on performance and outcomes as a form of closure and as a motivating factor to improve performance. Too often the dispatcher answers a cardiac arrest call, provides dispatcher-assisted CPR, and then moves on to the next call without ever knowing the outcome of the guidance and instruction, said a participant. In addition to education and feedback, Pepe reported that some breakout group members suggested the development of external dispatcher accreditation processes as another opportunity to fortify dispatcher education and preparation as well as instilling local pride in emergency medical department functions. One participant stated that providers should receive accolades for excellent performance.

To achieve these goals and advance dispatcher-assisted CPR nationwide, a few individuals suggested that NHTSA convene a stakeholder summit to develop an action strategy that would be focused on enhancing and expanding dispatcher-assisted CPR performance nationwide. Pepe noted that the resuscitation community should also consider engaging the National Conference of State Legislatures (NCSL), in part by inviting NCSL members to that national summit.

At a local level, Pepe called for increased involvement between EMS medical directors and the PSAP teams, noting that these types of strong partnerships and coordination can lead to better dispatcher performance, innovations, and improved outcomes. As in the discussions of community and public engagement, Pepe said that outreach and collaboration with local organizations, foundations, and advocacy groups could prove

exceptionally valuable in understanding both the needs and the potential barriers within those given communities.

BREAKOUT SESSION PREPORT: CONTINUOUS QUALITY IMPROVEMENT IN EMS SYSTEMS

Arthur Sanders, Planning Committee Member⁴

Arthur Sanders moderated the breakout session that discussed challenges and barriers related to continuous quality improvement programs in EMS systems, addressed in the IOM's fifth recommendation (see Appendix A). The group discussion focused on financing, messaging, and infrastructure to further continuous quality improvement initiatives. Sanders pointed out that measurement, benchmarking, and feedback/change are three interrelated elements that provide the foundation of any quality improvement effort within the resuscitation field, regardless of setting. Some breakout session members also identified a number of exemplary communities and systems that have effectively implemented continuous quality improvements, leading to better cardiac arrest outcomes. A few of the examples included efforts in Seattle/King County, Washington (e.g., the Resuscitation Academy), Arizona, and rural Wisconsin; the Take Heart America program in Minnesota; and the Resuscitation Outcomes Consortium experience.

Sanders first described the financing for EMS systems, stating that the mechanisms and policies that underpin EMS financing could be reassessed. EMS personnel are not currently paid as health care providers; they are only paid for transporting patients. This financing structure offers no incentives for providing high-quality care or improving the quality of care, said Sanders. Changing the status quo would likely require engaging the Department of Health and Human Services and the Department of Transportation through NHTSA. Sanders emphasized that EMS systems need to be viewed as providers rather than suppliers in order to establish incentives and align EMS care with the principles of value-based health care.

Sanders noted that messaging was a recurring theme that emerged from the plenary presentations and discussions. Communities should be encouraged to know their numbers in terms of survival rates, noted a

⁴ Breakout session presenters were asked to summarize the major ideas and opinions proposed by individual participants during their respective breakout sessions. Individual statements described below are not necessarily the position of the presenter and should not be interpreted as consensus statements from the breakout group as a whole or of the National Academies of Sciences, Engineering, and Medicine.

number of workshop participants. Sanders said that broader messaging to describe the magnitude of the problems and progress to date is also needed as a part of continuous quality improvement initiatives for EMS systems. He indicated that messaging and public engagement can serve as mechanisms to establish accountability across EMS systems and communities. The importance of uniform messaging reinforces the need for a collaborative of public, private, and governmental organizations to clearly define priority messaging to improve cardiac arrest survival.

The breakout group discussed building and expanding infrastructure for incentives and information exchange to promote continuous quality improvement programs across EMS systems. Sanders noted that there are several examples of demonstration projects with solid infrastructure (e.g., HeartRescue Project, the Resuscitation Academy, EMS Compass); however, the reach of these projects has been limited, and expansion efforts are needed. Some members of the breakout group reiterated the need for leadership and local champions to promote cultures of improvement and excellence, which could use existing infrastructure. Sanders also called for the development of performance measures that can be used to respond to local challenges, noting that performance measures could be tailored based on local needs. However, all EMS systems should be employing measures based on the locally collected performance data, some individuals said. Best practices, lessons learned, and general information from local EMS quality initiatives could be shared at regional and national meetings in order to motivate further improvement efforts, concluded Sanders.

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Enhancing Hospital Response to Cardiac Arrest

Hospitals and health care systems play major roles in optimal cardiac arrest response and treatment. Health care providers within these settings respond to cardiac arrests that occur on the premises (i.e., in-hospital cardiac arrests [IHCAs]); they facilitate smooth care transitions between emergency medical services (EMS) systems and hospital departments for out-of-hospital cardiac arrests (OHCAs); and they provide vital care after arrests. Variation in treatment, care delivery, and outcomes from one hospital to the next represents a significant opportunity to improve care across the United States (IOM, 2015a). Recommendations 4 and 5 from the Institute of Medicine's (IOM's) report describe mechanisms for developing and implementing standards of care and continuous quality improvement programs, which could serve as a basis for data collection and reporting (see Box 6-1).

CURRENT EFFORTS TO ACHIEVE HOSPITAL ACCREDITATION AND ACCOUNTABILITY IN CARDIAC ARREST

Mimi Peberdy, Virginia Commonwealth University

Hospitals' responses to cardiac arrest vary substantially across the United States, said Mimi Peberdy. Risk-adjusted survival rates for adults following range from 12 to 23 percent (Merchant et al., 2014), and survival rates tend to be worse at night and on weekends (Peberdy et al., 2008), Risk-standardized survival rates following IHCA also vary for children

BOX 6-1**Recommendations 4 and 5 from
*Strategies to Improve Cardiac Arrest Survival: A Time to Act*****Recommendation 4. *Set National Accreditation Standards Related to Cardiac Arrest for Hospitals and Health Care Systems***

The Joint Commission—in collaboration with the American Red Cross, the American Heart Association, hospital systems, hospitals, professional organizations, and patient advocacy groups—should develop and implement an accreditation standard for health care facilities specific to cardiac arrest care for adult and pediatric populations.

Recommendation 5. *Adopt Continuous Quality Improvement Programs*
Emergency medical services (EMS) systems, health care systems, and hospitals should adopt formal, continuous quality improvement programs for cardiac arrest response that

- assign responsibility, authority, and accountability within each organization or agency for specific cardiac arrest measures;
- implement core technical and non-technical training, simulation, and debriefing protocols to ensure that EMS and hospital personnel can respond competently to both adult and pediatric cardiac arrests; and
- actively collaborate and share data to facilitate national, state, and local benchmarking for quality improvement.

SOURCE: IOM, 2015a.

(Jayaram et al., 2014). Increases in survival rates between 2000 and 2010 also differ by hospital, ranging from 3 to 11 percent (Girotra et al., 2014). The rate of IHCA's differs greatly among hospitals, and increased rates of IHCA's have been associated with lower quality of care overall (Merchant et al., 2012).

In the United States, there are currently two organizations that provide guidance, standards, and quality measures related to cardiac arrest care in hospitals—the Joint Commission and the American Heart Association. Unfortunately, pilot programs to establish high-quality cardiac arrest performance measures experienced setbacks, and the Joint Commission never submitted measures to the National Quality Forum (NQF) for adoption. The American Heart Association also provides resuscitation guidelines for hospitals and uses data from the Get With the Guidelines–Resuscitation program to identify best practices and measures from the highest performing hospitals. The American Heart Association encour-

ages better performance and provides reward badges for improved performance, but participation is currently voluntary, said Peberdy. Thus, hospitals have little incentive to track resuscitation practices, which can lead to better outcomes.

There are many opportunities along the continuum of cardiac arrest care (i.e., before, during, and after resuscitation) where process measurement and modification could improve survival rates. "The best way to improve the outcome from a cardiac arrest is to prevent it from happening in the first place," said Peberdy. Many patients experience a period of abnormal vital signs hours before the arrest that often go unrecognized and untreated. Hospitals with the highest rates of unevaluated, abnormal vital signs are linked with the lowest rates of IHCA survival, noted Peberdy. To improve outcomes, hospitals could dedicate more attention to these prearrest indicators and attempt to prevent arrests from happening.

After a cardiac arrest occurs, it is important to track what happens before return of spontaneous circulation. Existing technologies and equipment can maximize resuscitation performance, stated Peberdy. For example, many defibrillators can measure quality and physiological effects of cardiopulmonary resuscitation (CPR) (e.g., rate and depth of compressions, end-tidal carbon dioxide monitoring, feedback on hyperventilation). Monitoring physiological data throughout resuscitation has been connected with better survival rates and neurological outcomes (Sutton et al., 2016). Although these tools and data are readily available, said Peberdy, there are no guidelines or standards telling hospitals how these data should be measured and applied to improve care.

Resuscitation team composition and training offer other opportunities to enhance survival rates. Current Joint Commission standards generally require hospitals to have resuscitation services and equipment available, a trained response team, and data collection to monitor performance. These standards are vague, said Peberdy. They do not define optimal team composition, the necessary training and skill level of the team members, or how resuscitation skills should be retained (e.g., training modalities, frequency or intensity of training, and continuing education). Many team members may see only one or two cardiac arrests per year, and often the team members have never worked together. Successful teamwork requires high-quality training to ensure rapid response and resuscitation, reducing delays in defibrillation times and death rates (Chan et al., 2008). Peberdy suggested that crew resource management training, a method used in the aviation industry, could be applied in hospital settings to foster better team responses to cardiac arrest.

Postarrest care is a relatively new area of study. It offers additional opportunities to improve data collection and knowledge about factors influencing cardiac arrest survival rates, explained Peberdy. Some exam-

ples of important metrics include withdrawal of life support and electroencephalographic monitoring.

Peberdy noted that errors in cardiac arrest care are common, and these errors have been shown to decrease the likelihood of return of spontaneous circulation and survival. Yet failures to document critical clinical interventions persist. For example, one study found that placement of the endotracheal tube was not documented in 17.5 percent of cases observed, indicating either a documentation problem or a clinical practice problem, said Peberdy (Phelan et al., 2013).

Reducing variability and pursuing improvements in IHCA processes and outcomes will require mandatory performance measurement that includes quality measures that are based on reliable data sources and appropriately risk adjusted, said Peberdy. For example, presence of comorbid conditions, the existence of do-not-resuscitate orders, and resuscitations that occur in intensive care units should all be adjusted for when evaluating mortality, said Peberdy. Unfortunately, high-volume or high-target quality measures (e.g., survival) for hospital-based resuscitation are difficult to select, implement, and interpret, said Peberdy. She suggested developing smaller interim performance and outcome measures along the entire sequence of resuscitation events rather than focusing solely on the final outcome—neurologically intact survival to hospital discharge. Peberdy concluded, “the only thing we cannot afford to do, is to do nothing.”

One workshop participant highlighted a 2015 IOM report called *Vital Signs: Core Metrics for Health and Health Care Progress* (IOM, 2015b). The report noted that the expanding number of mandatory process measures is becoming burdensome to providers without evidence of improved outcomes. The report recommended a set of core measures meant to improve health, quality, cost, and engagement. The participant suggested that the resuscitation field may be better served if all hospitals and EMS systems track and report outcomes along with the best practices associated with changes in outcomes rather than asking the Joint Commission to assess specific process measures. Vinay Nadkarni, another panelist, generally agreed, but also emphasized appropriate risk adjustment. He also suggested the application of a few time-critical performance measures, called tracers, that all hospitals could easily measure and report.

CHILDREN AND CARDIAC ARREST: IMPLICATIONS OF THE IOM REPORT

*Vinay Nadkarni, Children's Hospital of Philadelphia,
University of Pennsylvania Perelman School of Medicine*

Each day approximately 1,000 adults and 50 children experience a cardiac arrest in North America, began Vinay Nadkarni. Given current survival rates, this is the equivalent of two Boeing 747 airplanes full of adults and two small school buses full of children crashing every day with no survivors, he explained. Estimates suggest that adults lose about 10,000 quality-adjusted life years (QALYs) per day following a cardiac arrest, whereas children lose approximately 3,500 QALYs per day (Nadkarni, 2016). Because children usually arrest at very young ages and have a long life span, the public health burden is high. In addition to the two chains of survival for adult populations—one for IHCA and one for OHCA—there is also a third chain of survival that is dedicated to pediatric cardiac arrest, which places an increased emphasis on prevention of injury and cardiac arrest in pediatric populations, stated Nadkarni.

The etiology of cardiac arrest in children and babies differs from that in adults. The predominant causes of cardiac arrest in children are usually respiratory or hypoxic in nature, unlike the underlying coronary artery disease that often leads to arrest in adults, noted Nadkarni. At birth many babies require some form of immediate stimulation, whereas only 3 to 6 percent of the 136 million births annually worldwide require bag-and-mask ventilation and less than 1 percent require more advanced resuscitation (e.g., CPR, medication) (Lee et al., 2011).

In the United States, 80 percent of pediatric emergency room visits occur in community hospitals, not specialized children's hospital settings (Nadkarni, 2016). Therefore, all hospitals need to be prepared to treat pediatric cardiovascular emergencies and cardiac arrest, he stated. Resuscitation interventions for pediatric populations are similar to those used for adults. In the prearrest phase, early identification and rapid response are paramount. During cardiac arrest, high-quality CPR, ventilation, and defibrillation for shockable rhythms are key elements of response. Health care providers should also consider the use of vasopressors and administer treatments for reversible causes of the arrest when applicable. In selected settings, extracorporeal cardiopulmonary resuscitation, extracorporeal membrane oxygenation (ECMO), and bypass CPR are also available for eligible pediatric patients. In the postarrest phase, the intervention targets in pediatric patients are generally the same as those in adult populations: targeted temperature management, blood pressure maintenance, oxygenation, ventilation, recognition and treatment of sei-

zures, and percutaneous coronary intervention (PCI) or thrombolysis, as necessary.

Preparing health care providers to respond to pediatric cardiac arrest can be accomplished through low-intensity, high-frequency training, said Nadkarni. Simulation, hands-on practice, real-time CPR feedback, and team prebriefing and debriefing are effective components of a team-based hospital training program. To evaluate readiness and team performance, simulation of identical pediatric cases can be applied across emergency departments or hospitals. The International Network for Simulation-based Pediatric Innovation, Research, & Education (INSPIRE) and ImpACTS investigators have developed a demonstration project that is being implemented in 30 hospitals (Auerbach et al., 2016). The project uses simulation to measure and compare performance scores on a range of cardiac arrest measures, such as appropriate compression and ventilation rates, use of a backboard, no interruptions in compressions, among many others. Nadkarni noted that the findings from this demonstration could be translated into Joint Commission or NQF quality measures, which could eventually be used to evaluate hospitals for readiness, teamwork, and time-critical performance.

The Get With the Guidelines–Resuscitation program includes a number of performance measures that could easily be adapted, measured, and compared across adult, pediatric, and neonatal populations in hospitals, suggested Nadkarni. For example, in adults and children, the administration of epinephrine within 5 minutes for arrests with asystole or pulseless electrical activity is a meaningful performance measure, but likely would need to be substituted for neonate populations due to lack of evidence. In the neonate population, the application of positive pressure ventilation within 1 minute of birth could be used as a comparable type of measure, suggested Nadkarni.

The research challenges for resuscitation research remain the same regardless of the population. There are challenges related to collecting data and ensuring its quality, processing research findings into knowledge, transferring that knowledge into guidelines and standards, and teaching those standard and guidelines to prompt actions that will benefit patients and improve outcomes. Specifically, Nadkarni highlighted obstacles in training teams and assessing performance in simulated environments and then being able to correlate simulated performance with real performance and meaningful clinical outcomes data.

In response to a question about the possible benefits and opportunities for collecting cardiac arrest data in hospitals, Nadkarni stated that the use of electronic health records (EHRs) for data collection in some ways represents the holy grail. The Get With the Guidelines program, for example, has partnered with the largest EHR companies to attempt to

develop pathways that allow relevant data (e.g., defibrillator sequence, electrocardiogram rhythms) to be transferred to the registry. Thus, the ability to transfer data automatically could facilitate quality improvement efforts. However, EHRs do not always capture what was actually done nor do they accurately account for time as a variable, Nadkarni said. Because many of the cardiac arrest processes are time critical, identifying start and end points and measuring time as a reliable and synchronized variable are beneficial. Dianne Atkins, the planning committee member who moderated this panel, described a CPR navigator module that her health care system designed to collect cardiac arrest data. Although data are often recorded after an event, the module is meant to be used in real time. Mobile computers in hospital units allow nurses to quickly record actions taken (e.g., epinephrine administered, ventilation provided) during the event by simply checking boxes.

FROM PLAYBOOK TO POLICY: ANTIMICROBIAL STEWARDSHIP

Edward Septimus, Hospital Corporation of America Healthcare System

Despite obvious differences between sepsis and cardiac arrest, a number of important similarities may prove informative, Septimus explained. Prevention, early recognition and response, and risk-adjusted outcomes are common elements of concern for health care providers and researchers in both the infectious disease and resuscitation fields. For leaders in both fields, there are two pathways forward, he said: “We can either put our heads in the sand and wait for a crisis to develop or we can proactively come up with some successful strategies before regulatory levers force action.” One of the key conclusions from the IOM report *Crossing the Quality Chasm* noted that it takes an average of 17 years for best practices to take hold (IOM, 2001). That is far too long to wait, said Septimus—patients deserve better. Reiterating opening remarks from Tom Aufderheide, Septimus supported the development of collaborative action to overcome cultures of inaction in the health care field.

When asked about major advances in public health during the past century, most experts cite the discovery of antibiotics and vaccines. However, in recent years the world has experienced setbacks in both of these areas, said Septimus. The overuse and misuse of antibiotics across the continuum of care and in animals has led to antimicrobial resistance, which is having adverse effects on patients and societies worldwide. In fact, the World Health Organization considers antimicrobial resistance to be an emerging threat to global stabilization.

Similar to the challenges that the resuscitation field faces with improving rates of CPR and cardiac arrest outcomes, antimicrobial resistance is

a complex and persistent problem that requires changes in physician behavior and public awareness. Unfortunately, this is not a new problem, and little has been done to rectify the situation, said Septimus.

Collaborative Action to Stem Antimicrobial Resistance

In 2015 the President's Council of Advisors on Science and Technology (PCAST) released a report titled *The National Action Plan for Combating Antibiotic-Resistant Bacteria* (PCAST, 2015). Septimus noted there were a number of recommended public policy changes that were similar to the recommendations in the IOM's report on cardiac arrest. For example, the PCAST report called for the development of accreditation standards—similar to the fourth recommendation in the cardiac arrest report. The report also recommended tracking of inpatient and outpatient antibiotic use and annual reporting, which is similar to many aspects of the registry recommended in the IOM report's first recommendation. The PCAST report also called for hospitals and health care settings to better align and comply with the Centers for Disease Control and Prevention's (CDC's) Core Elements of Hospital Antibiotic Stewardship Programs (CDC, 2014), the Centers for Medicare & Medicaid Services's (CMS's) proposed rules related to antibiotic stewardship programs (CMS, 2016), and the Joint Commission's Antimicrobial Stewardship Standard (Joint Commission, 2016).

To accomplish the goals and objectives described in the PCAST report, a wide range of stakeholder support and engagement could be developed from many entities, including the White House, CDC, CMS, the Joint Commission, NQF, the American Hospital Association, key professional societies, and many others. Success will require strong leadership and accountability from within hospitals and across the health care system; the ability to reliably track, measure, and report on data and outcomes; the capability to develop, test, and modify interventions; and education for providers, patients, and families. Septimus noted that all of these actions mirror the actions that the resuscitation field will need to take to advance the recommendations from the IOM's 2015 report. However, in considering the development and application of process measures, Septimus said that all process measures must be linked to better outcomes; unintended consequences must be considered when developing and implementing new process measures; and reportable measures must not create a sizable burden on health care providers.

Building on the synergy of the PCAST report, NQF and CDC partnered with a group of public- and private-sector leaders—the Antibiotic Stewardship Action Team—in 2015 to develop the guide *National Quality Partners Playbook: Antibiotic Stewardship in Acute Care* (NQF, 2016). The

playbook is the collaborative product of more than 30 prominent government agencies, hospital organizations, consumer groups, professional organizations, and research centers. It was designed to provide hospitals, accreditation bodies, and patient and consumer groups with a common agenda, guidance, and achievable strategies for implementing a sustainable, effective stewardship program at the local level. The playbook is based on CDC's Core Elements and incorporates examples of success, possible solutions to common barriers, potential measurement strategies, and viable future directions. Septimus said the playbook was not meant to be a mandatory must-do list, but rather a resource of options that can be adopted depending on local circumstances, needs, and available resources.

Numerous lessons from the development of the playbook can be transferred to the resuscitation community. First, the playbook was developed by convening a diverse group of national experts from leading organizations who reinforced antimicrobial stewardship as a national priority. This effort was not unlike the dissemination workshop and collaborative efforts being discussed at the workshop, noted Septimus. Additionally, Septimus emphasized the importance of engaging and collaborating with patients and consumers throughout the entire process, saying that these individuals can provide indispensable passion, advocacy, and powerful personal stories that can motivate change. Rather than adding a new layer of guidance, the playbook aligns perfectly with and builds on existing and proposed guidance from CDC, CMS, and the Joint Commission. It provides actionable suggestions and examples that can be adopted by organizations regardless of size or budget, so it is scalable and manageable for all systems. The online edition of the playbook also links to critical resources that can be leveraged for success. Following the success of the playbook, there have been discussions among the partners about using the same collaborative model to develop a playbook for long-term care.

BREAKOUT SESSION REPORT: IMPROVING THE QUALITY OF HOSPITAL RESPONSE TO CARDIAC ARREST

Dianne Atkins, Planning Committee Member¹

Atkins facilitated a breakout session on improving the quality of hospital response to cardiac arrest, which responded to the fourth recommendation in the IOM's report (see Appendix A). The breakout group consid-

¹ Breakout session presenters were asked to summarize the major ideas and opinions proposed by individual participants during their respective breakout sessions. Individual statements described below are not necessarily the position of the presenter and should

ered a range of strategies that could be used to more broadly enhance the quality of hospital response and care for cardiac arrest.

Atkins highlighted some of the major barriers identified in her breakout session relevant to quality improvement, many of which relate to challenges with data collection and availability. For example, Atkins pointed out that in general there is a resistance within hospitals against publicly reporting data and that existing data are inadequate. The lack of specificity in coding to distinguish IHCA from OHCA and the inadequacy of Current Procedural Terminology (CPT) codes for cardiac arrest treatments also present challenges for establishing and implementing accreditation standards. A number of workshop participants commented on challenges associated with data collection and analysis and how these challenges impede progress in quality improvement efforts. Three participants described limitations of current coding systems, noting that the lack of separate codes for in-hospital, out-of-hospital, and pediatric cardiac arrests created problems when trying to conduct research related to cardiac arrests that occur in a specific setting or population. One of these participants also noted that the lack of available coding for specific cardiac arrest therapies (e.g., therapeutic temperature management) creates difficulties for health care systems that want to study outcomes following various treatments.

Factors related to risk adjustment and differentiating between standards and metrics are also challenges that will need to be resolved, noted Atkins. To overcome these challenges and move forward with development and adoption of accreditation standards, strong leadership within the hospitals will be required, said Atkins. Individual participants in the breakout group also identified a range of stakeholders that should be consulted throughout the development and implementation phases (see Box 6-2).

Atkins noted that the breakout session members identified a number of steps that would likely need to occur before accreditation standards could be broadly implemented. For example, hospital recognition programs could be developed to encourage the adoption of process and quality improvement initiatives within hospitals, similar to the Get With the Guidelines programs in resuscitation, stroke, and myocardial infarction. These programs can reward participation and recognize benchmark achievements, said Atkins, while collecting data relevant to process improvement and adherence to existing guidelines. This approach benefits from a gradual rollout and tailoring to the needs of hospitals, but it is completely voluntary. Some members of the breakout group

not be interpreted as consensus statements from the breakout group as a whole or of the National Academies of Sciences, Engineering, and Medicine.

BOX 6-2
**Stakeholders to Engage When Developing
Accreditation Standards for Cardiac Arrest**

- **Accreditation Organizations:** Joint Commission, National Committee for Quality Assurance, and National Quality Forum
- **Coding Organizations:** Organizations that are connected with the development and adoption of Current Procedural Terminology (CPT) codes and *International Classification of Disease (ICD)* codes (e.g., American Medical Association, National Center for Health Statistics)
- **Government Agencies:** For example, Centers for Medicare & Medicaid Services
- **Industry**
- **Patient and Family Advocacy Organizations**
- **Professional Organizations:** For example, American Academy of Pediatrics, American Heart Association, American Hospital Association, Children's Hospital Association, Society for Critical Care Medicine, Society of Hospital Medicine

SOURCE: Presented by Dianne Atkins, July 12, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*.

also suggested the development of cardiac arrest centers of excellence or cardiac arrest-ready hospitals in order to identify hospitals that provide high-quality, evidence-based care for cardiac arrest patients (see also Chapters 2 and 7). Atkins noted that combining these two strategies could naturally lead to the development of metrics and standards, which could then be implemented more broadly.

Other members of the group suggested that quality improvement efforts for cardiac arrest be closely tied to patient safety initiatives and team training opportunities. For example, two workshop participants suggested using prehospital providers (e.g., paramedics) as instructors to provide CPR and resuscitation training to response teams in hospital settings. In considering implementation of improvement efforts, Atkins warned that process variability and technological challenges across settings are common and will need to be considered. Several breakout participants also discussed the potential value of developing a cardiac arrest coalition and playbook, similar to the *National Quality Partners Playbook: Antibiotic Stewardship in Acute Care* (NQF, 2016). Although engaging a wide range of stakeholders could be difficult, the coalition and playbook could provide a national roadmap for ensuring high-quality, evidence-

based cardiac arrest care across hospital and health care settings throughout the United States, said Atkins.

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Effective Collaboration for Cardiac Arrest

The recommendations from the Institute of Medicine's (IOM's) report described a range of high-priority actions that could elevate the resuscitation field. Collaborative action across numerous organizations and institutions has led to progress over the past few decades. However, more formalized and sustained collaboration will be necessary to further advance resuscitation science and cardiac arrest surveillance, translate research findings into widely used evidence-based treatments and care, and achieve better survival rates and outcomes across the United States (IOM, 2015). Recommendation 8 from the IOM report describes the creation of a National Cardiac Arrest Collaborative, which could be used to bring unity to the resuscitation field, define shared goals, and continue the momentum that was created following the release of the IOM's report (see Box 7-1).

FROM THE IOM REPORT TO FORMAL COLLABORATION: EXAMPLES OF SUCCESS

*Vicky Whittemore, National Institute of
Neurological Disorders and Stroke,
National Institutes of Health*

In the late 1980s, the American Epilepsy Foundation invited two epilepsy organizations—the Epilepsy Foundation and Citizens United for Research in Epilepsy (CURE)—to join them for a meeting to discuss

BOX 7-1**Recommendation 8 from*****Strategies to Improve Cardiac Arrest Survival: A Time to Act*****Recommendation 8. Create a National Cardiac Arrest Collaborative**

The American Heart Association and the American Red Cross—with the U.S. Department of Health and Human Services and other federal agencies, national and international resuscitation councils, professional organizations, private industry, and patient advocates—should establish a National Cardiac Arrest Collaborative to unify the cardiac arrest field, identify common goals, and build momentum within the field to ultimately improve survival from cardiac arrest with good neurologic and functional outcomes. The Collaborative should

- provide a platform for information exchange about key successes and failures in different systems and settings and for stakeholder communication about new research findings and initiatives;
- convene working groups on short- and long-term national research priorities for cardiac resuscitation and postarrest care, which focus on critical knowledge gaps (e.g., the impact of care transitions; the organization, composition, and training of resuscitation teams; optimal timing of initial neurological evaluation; and appropriate withdrawal-of-care protocols);
- develop action strategies related to health policy, research funding and translation, continuous quality improvement, and public awareness and training;
- produce and update toolkits for different stakeholders (e.g., emergency medical services [EMS] systems, hospitals, local health departments, and local health care providers) in order to facilitate effective system and individual responses to cardiac arrest;
- hold an annual collaborative meeting in conjunction with a regularly scheduled health professional conference to discuss short- and long-term goals and progress; and
- encourage public–private partnerships to support activities that focus on reducing the time to defibrillation for cardiac arrest, including the development of technologies to facilitate automated external defibrillator registries for use by the public, EMS systems, and other stakeholders.

SOURCE: IOM, 2015.

opportunities to partner in research funding and advocacy for epilepsy. The name of the coalition, *Vision 2020*, originated from the vision that the early member organizations had for how epilepsy should be treated and publicly accepted by the year 2020, said Vicky Whittemore. The prelimi-

nary goals of Vision 2020 were to provide the American Epilepsy Society¹ with the patient and family perspective, advocate for research funding on Capitol Hill, and serve as a support network and source of information for the many advocacy organizations across the epilepsy community. Each year the members of Vision 2020 met at the American Epilepsy Society's annual meeting to discuss priorities. Over the years, the coalition grew to include more than 30 patient advocacy organizations and federal agencies, such as the Centers for Disease Control and Prevention, the National Institutes of Health (NIH), and the Department of Veterans Affairs.

In 2010 the members of Vision 2020 came together with additional funders to commission an IOM study on the public health aspects of epilepsy. In 2012, the IOM released the product of the study, a report called *Epilepsy Across the Spectrum: Promoting Health and Understanding* (IOM, 2012). The IOM report featured six recommendations that called on Vision 2020 to take action in areas related to improving the delivery of care, expanding educational opportunities for individuals with epilepsy and their families, informing the media, coordinating public awareness initiatives, and expanding collaborations to further strengthen advocacy efforts.

Maintaining Momentum Following the IOM Report

Following the release of the IOM report, Vision 2020 continued holding its monthly conference calls and discovered that the member organizations enjoyed working together closely. Additionally, there were a number of common areas in which the member organizations could coordinate, share information, and support each other. At that point, Whittemore said, the members of Vision 2020 determined that they needed to reorganize themselves to better accommodate the expanded membership and to strategically implement the recommendations from the IOM report. The primary objective of the reorganization was to establish effective, efficient operations and a structure that would streamline priority setting and decision making, improve leadership and accountability, and maximize joint fundraising activities. The purpose of the fundraising would be to collect resources that could be used to support specific collaborative projects as well as staffing needs for the collaborative.

During the reorganization process, the members agreed to remain under the auspices of the American Epilepsy Society rather than establishing their own independent 501(c)(3) organization, noted Whittemore. The

¹ The American Epilepsy Society is a professional organization that encompasses clinicians, researchers, and patient advocates who are all focused on clinical care and research for epilepsy.

members also agreed to rebrand the coalition as the Epilepsy Leadership Council. The leaders of the Epilepsy Leadership Council's member organizations came together to develop a charter and operating principles that all the organizations could support, said Whittemore. There is a sliding scale for membership dues, which are based on the annual budget of each organization. Whittemore also noted that the American Epilepsy Society has been very generous by providing staff support as the Council got off the ground. Now that the Council is operational, it will begin developing proposals and seeking additional funding to support agreed-upon projects.

The core of the Epilepsy Leadership Council's mission is "to serve as a mechanism through which organizations can work on shared goals and projects that will have a positive impact on the lives of individuals with epilepsy," said Whittemore. The second part of the mission highlights a focus on "areas where working together produces greater efficiency and impact than working independently," noted Whittemore. This mission encourages the member organizations to collaborate without duplicating the efforts of any one organization. Given the diversity of the types of organizations that belong to the Epilepsy Leadership Council, the members decided to establish a 12-member leadership board, which was meant to be fairly balanced across the types of organizations. Whittemore observed that since the reorganization the board has been functioning very well, with all of the board members having an equal voice regardless of the size of the organization they represent.

In 2015, the IOM hosted a dissemination meeting that focused on progress that had been made since the release of the report in 2012. For example, a new app and website dedicated to empowering individuals with epilepsy to seek more information had been released and was featured on websites of all members of the Epilepsy Leadership Council (Vision 20/20 Partner Groups, 2016). Additionally, the National Association of Epilepsy Centers had implemented an accreditation process for epilepsy centers, which was a recommendation from the IOM report. During the dissemination meeting, the Epilepsy Leadership Council also described how it has collaborated to develop plans and priorities for research, education, and advocacy activities across the epilepsy field.

Whittemore reflected on some of the challenges that have faced the Epilepsy Leadership Council as it has evolved, noting that the board members are all volunteers who are busy with full-time jobs, running their own organization, or doing both. Therefore, the volunteer work is often a secondary priority. One of the biggest challenges for the Epilepsy Leadership Council has been determining which comes first—membership dues/funding or developing project plans. "You cannot do projects or make plans without funding, but you cannot get funds without having

plans or projects,” said Whittemore. Priority setting across such a large and diverse group of organizations has also presented some challenges, said Whittemore, but, overall, the organizations have managed to agree on common priorities.

A number of lessons from the collaborative efforts of Vision 2020 and subsequently the Epilepsy Leadership Council may be beneficial to the resuscitation field, said Whittemore. The various organizations that participate in the collaborative are all there for different reasons. Thus Whittemore reiterated the importance of focusing on activities in which collaboration will lead to better outcomes. Having a neutral party to help facilitate discussion and keep everyone focused on selected priorities is helpful. Whittemore also noted that staffing is critical to the success of any collaborative, saying that it is important to have a dedicated individual tracking all of the pieces and moving things forward. Generally, the Epilepsy Leadership Council and its collaborative nature have been attractive to industry stakeholders, said Whittemore. Rather than having to work across multiple organizations to support a public awareness campaign, for example, the funder can interact with one central entity.

COLLABORATION AND NATIONAL QUALITY IMPROVEMENT EFFORTS IN STROKE

Mark Alberts, University of Texas Southwestern Medical Center

Numerous commonalities can be identified across the trauma, stroke, and cardiac arrest fields, said Mark Alberts. For example, trauma, stroke, and cardiac arrest all occur without warning and have a limited timeframe for effective response and intervention, and they all require a multidisciplinary team to provide and improve care. Based on these similarities and the lessons that can be leveraged from trauma and stroke centers, Alberts hypothesized that “a national network of cardiac arrest centers will improve the care and outcomes of patients with cardiac arrest.”

Since the development of trauma and stroke centers, studies have demonstrated improved patient outcomes. For example, the use of trauma centers has been associated with reductions in different causes of mortality (Nathens et al., 2000, 2001). Similarly, patients treated in designated stroke centers—primary or comprehensive—experience reduced rates of mortality when compared with patients treated in non-designated hospitals, with comprehensive centers linked to the lowest rates of mortality (Meretoja et al., 2010; Xian et al., 2011). The distribution of trauma and stroke centers has posed challenges for ensuring equitable access for patients (e.g., Figure 7-1) and will also be a concern for cardiac arrest cen-

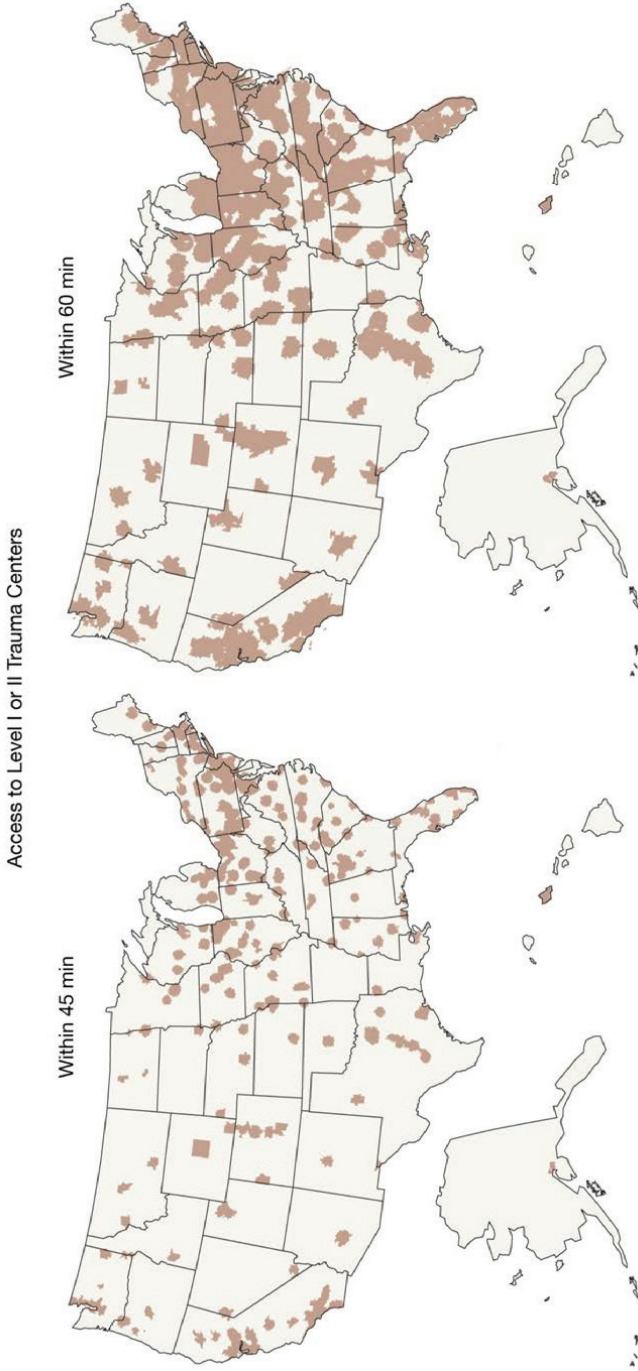


FIGURE 7-1 Distribution of level I or level II trauma centers across the United States accessible by ambulance or helicopter. SOURCE: Presented by Mark Alberts, July 12, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act* (citing Branas et al., 2005).

ters, said Alberts. The goal should be to create a system in which patients will have access to higher levels of care regardless of where they live.

Lessons from the Brain Attack Coalition and the Stroke Center Initiative

The Brain Attack Coalition is a multidisciplinary group of more than a dozen organizations and government agencies that is “dedicated to setting direction, advancing knowledge, and communicating the best practices to prevent and treat stroke” (BAC, n.d.). The Brain Attack Coalition falls under the auspices of the National Institute of Neurological Disorders and Stroke (NINDS). Thus, NINDS provides a significant amount of support and infrastructure, such as meeting space and staff support, said Alberts. The Brain Attack Coalition is chaired by a former head of the stroke program at NINDS who volunteered to take on the role after retirement, said Alberts. The membership of the Coalition is determined by the parent organizations. Overall, there has been a sense of shared ownership and commitment. Although none of the organizations have veto power, noted Alberts, they all have a place at the table and provide input on the major decisions that the Coalition makes. To date, the Coalition has not accepted any sponsorship from industry sources. The organizations pay travel expenses two or three times per year for members to attend the Coalition’s meetings, which are held on the NIH campus.

Over the years the Coalition has supported activities related to public and professional education about stroke, such as NIH’s stroke scale. The Coalition provides a platform that allows the stroke field to speak with one voice and more easily coordinate with non-member organizations and agencies, such as the Centers for Medicare & Medicaid Services, the Food and Drug Administration, and the Joint Commission. Alberts noted that recommendations from the coalition are widely supported and viewed as highly credible because of the diverse nature of the membership, which includes representatives from most of the major organizations in the stroke field. As with any large coalition, the decision-making process can be cumbersome, and competing priorities may lead to disagreements. However, the shared goal is to keep the process moving forward and come to a consensus on a final product that all of the member organizations will support.

In 2000 the Brain Attack Coalition launched an initiative to recognize hospitals that provide high-quality stroke care as designated stroke centers. This initiative galvanized the Coalition by giving it a concrete focus and structure. As the stroke center initiative got under way, the first challenge, said Alberts, was verifying that the hospitals were consistently meeting requirements related to staffing, infrastructure, care proto-

cols, and outcomes. The initiative experienced a tremendous boost when the Joint Commission began offering a formal certification for hospitals because there are certain expectations associated with Joint Commission certification, said Alberts. Once hospitals started to market themselves as certified stroke centers, other hospitals also sought certification, thus expanding the network of stroke centers in the United States. Subsequently, the Healthcare Facilities Accreditation Program and DNV GL also established certification programs for stroke centers. Today, there are more than 1,500 primary stroke centers and 200 comprehensive stroke centers nationwide (Alberts, 2016).

Since the implementation of the certification system, Alberts said that most states have developed a stroke system of care that includes a stroke triage or diversion paradigm. Some states used the Joint Commission certification as a basis for state certifications that allow emergency medical services (EMS) systems to alter their transport protocols, thus bypassing non-stroke-center hospitals when transporting a stroke patient. Following the development of regional triage protocols, EMS systems had concerns about bypassing nearby hospitals. However, Alberts and his colleagues conducted a survey in Chicago to determine whether hospitals were dissatisfied with the stroke triage protocols. He said that approximately a third of hospitals indicated they had no problem being bypassed and would rather not receive stroke patients because stroke was not an area of interest. If the resuscitation field decides to pursue a similar model, Alberts speculated there would be a comparable response from hospitals regarding cardiac arrest care in designated centers.

The diversity of EMS systems across the United States also presented some coordination challenges. In Illinois, which has 16 distinct EMS regions, local EMS systems were empowered to develop their own protocols, if they did not agree with the suggested triage protocol. However, all EMS systems were required to participate and report on metrics. As the regional triage protocols were implemented, there were concerns about overcrowding the stroke centers and extending EMS transportation times to the designated centers. However, the market essentially resolved those concerns, said Alberts. In urban areas, multiple hospitals became certified as primary stroke centers, in part because they wanted to be competitive. Therefore, problems with overcrowding and long transport times have not been observed.

Alberts offered the resuscitation field a range of advice on how to establish a national network of cardiac arrest centers. Reiterating the parallels among stroke, trauma, and cardiac arrest, Alberts suggested adopting a three-tiered system similar to those that have been used for trauma (i.e., Levels I, II, and III) and stroke (i.e., ready to handle comprehensive, primary, and acute stroke). Regardless of whether the arrest

occurs inside or outside of the hospital, he said that all designated centers should be able to provide a baseline of care. Alberts emphasized the need to develop a system that is flexible and also capable of tracking outcomes. Protocols should evolve based on available data and current standards of care, said Alberts. For example, endovascular therapy for acute stroke was not available in 2005, when the paper outlining the roles of comprehensive stroke centers was published. Thus the protocols had to be updated when that treatment became part of the care paradigm. Alberts restated the importance of collaboration as a pillar of success, saying that the resuscitation field would benefit from a coalition similar to the Brain Attack Coalition. When inevitable disagreements occur among coalition members, Alberts said, “always ask ‘what’s best for the patient?’ The answer will guide you to the best path forward.”

BREAKOUT SESSION REPORTS: ESTABLISHING A CARDIAC ARREST COLLABORATIVE

*Tom Aufderheide, Richard Bradley, and Lance Becker,
Planning Committee Members²*

Tom Aufderheide, Lance Becker, and Richard Bradley facilitated the three breakout sessions that focused on establishing a cardiac arrest collaborative—Recommendation 8 in the IOM’s report (see Appendix A). The three groups considered potential stakeholders to engage, the definition and value of a cardiac arrest collaborative, barriers and opportunities to establishing such a collaborative, and potential next steps. Aufderheide, Bradley, and Becker all indicated that a number of breakout group members supported establishment of a national cardiac arrest collaborative. Aufderheide said that no one in his group believed there would be a downside to establishing such a collaborative. Becker said many individuals in his breakout group favored using a collaborative to develop unified, patient-centered goals and messaging.

Individual participants in all three breakout groups suggested wide involvement that goes beyond the cardiac arrest community to include other medical specialties, consumer groups, industry, sports organizations, and many others (see Box 7-2). Bradley noted that the role of industry would need to be considered and defined in the early stages of

² Breakout session presenters were asked to summarize the major ideas and opinions proposed by individual participants during their respective breakout sessions. Individual statements described below are not necessarily the position of the presenter and should not be interpreted as consensus statements from the breakout group as a whole or of the National Academies of Sciences, Engineering, and Medicine.

planning. One workshop participant called for the inclusion of experts in marketing, branding, and communications, noting these are not necessarily areas in which researchers excel.

Defining the Purpose of a Collaborative

When defining the purpose of a collaborative, some participants in Aufderheide's breakout group noted that the collaborative could pursue continuous innovation within the resuscitation field and achieve collective goals (e.g., improving patient outcomes) that may be unattainable through the separate actions of individual organizations or stakeholders. Some members of Bradley's breakout group suggested that the collaborative focus on a shared agenda and collective goals, while building synergy. Other participants discouraged using the collaborative as a standards-setting organization. Becker noted that the organizers will need to have a discussion about definitions and clarify the distinction between the collaborative and collaboration and what those differences will mean for how the partner organizations interact.

Numerous benefits of the collaborative were noted in the three breakout groups. The collaborative could promote inclusivity, participation, and leadership by maintaining a neutral position and managing conflicts of interest and competition among member organizations, said Aufderheide. Some members of Bradley's breakout group stressed the need to balance conflicts of interest across all participating groups, including industry. Other participants encouraged the collaborative to develop a set of toolkits and other materials for EMS systems and hospitals to use in deploying continuous quality improvement programs at local and regional levels. Aufderheide suggested that a collaborative could induce cultural changes related to the public, EMS systems, and hospitals and could also serve as a platform for funding opportunities. Bradley said the collaborative could have a greater impact on policy changes through synchronized messaging.

Individual participants in all three breakout groups identified many changes to forming a collaborative. Aufderheide and Bradley said that determining and coordinating membership, establishing governance and an effective mission, and developing operational processes would be among the primary hurdles. Bradley warned against becoming unduly bogged down with the development phase and administrative details. Aufderheide indicated that keeping the collaborative focused on shared objectives without impeding the work of individual organizations may also pose challenges. However, some members of Bradley's breakout group saw this as a benefit, noting that the collaborative would allow several organizations to work in harmony and speak with one voice

BOX 7-2
**Examples of Stakeholders to Engage in a
 National Cardiac Arrest Collaborative**

- **Accreditation and Certification Organizations:** emergency medical services personnel, hospitals, nursing
- **Cardiac Arrest Survivors and Organizations:** survivors, families and friends of survivors and non-survivors, and rescuers
- **Consumer Organizations:** AARP
- **Government Agencies:** Centers for Disease Control and Prevention, Department of Education, Food and Drug Administration, National Highway Traffic Safety Administration, National Institutes of Health, and other relevant Department of Health and Human Services agencies
- **Health Care Providers and Medical Specialty Organizations:** anesthesiology, cardiology, critical care, dentistry, emergency care, neurology, post-resuscitation care and counseling, and rehabilitation
- **Industry**
- **Marketing, Branding, Communication, and Strategic Planning Organizations**
- **National Associations for State and Local Leaders:** governors, mayors, health officials (e.g., National Association of County and City Health Officials)
- **Research Community:** individual researchers and existing research collaboratives
- **Resuscitation Guidelines and Training Organizations:** American Heart Association, American Red Cross
- **Sports-Related Organizations:** college sports associations (e.g., National Collegiate Athletic Association), professional athletes, and professional sports organizations (e.g., National Football League)

SOURCE: Presented by Tom Aufderheide, Lance Becker, and Richard Bradley, July 12, 2016, A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*.

without losing their individuality. Aufderheide, Becker, and Bradley, all remarked that developing a sustainable model with sufficient funding would be critical to success. Becker said that all participating organizations should contribute funding to support the collaborative, but a sliding scale could be used to ensure participation was not cost prohibitive to smaller organizations.

Two breakout sessions discussed possible short- and long-term goals and initiatives for the collaborative. Becker and Bradley both noted that one short-term goal could focus on public education to overcome the culture of inaction and increase rates of bystander cardiopulmonary resusci-

tation (CPR). Some breakout group participants also suggested setting a goal to improve EMS performance by more broadly adopting evidence-based practices. Becker said that expanding dispatcher-assisted CPR is a short-term goal that could have a marked effect in many communities. He also noted that, although surveillance would be a major long-term goal, discussions about how to conduct surveillance should happen in the short term. One workshop participant suggested the formation of subcommittees or task forces to tackle specific goals or areas, noting that the combination of goals and the recommendations from the IOM report may be too much for one group to solve. Furthermore, the collaborative could develop regular reports on the state of cardiac arrest and cardiac arrest care in the United States that also set national priorities for improving care, said Bradley.

In terms of long-term priorities, Bradley suggested working toward a national cardiac arrest registry that encompasses both EMS and hospital care. The registry could set goals and test programs to sustain and expand gains in bystander CPR rates and survival rates with good neurological outcomes. Becker called for establishing cardiac arrest as a reportable condition and suggested that the collaborative could play a role in advocating for updated diagnostic and billing codes. Another long-term priority, reported Becker, could be to adapt the Brain Attack Coalition model and develop a three-tiered designation system for hospitals that provides high-quality cardiac arrest care from basic to advanced levels.

Next Steps in Building a National Collaborative

Individual participants in Aufderheide's group proposed two alternate strategies for next steps. The first option was to convene a relatively small group of representatives from key organizations (10 to 20 individuals) to initialize the planning phase of the collaborative—discussing funding models and membership, considering operational structures, and developing preliminary objectives. However, some breakout session participants expressed concern about transparency and lack of inclusivity with this approach.

The second option involved hosting a planning meeting with the key organizations and offering an opportunity for commentary and input either in real time or following the meeting for stakeholders not at the planning meeting. A few attendees urged organizers to hold the planning meeting within 3 to 6 months of the IOM's dissemination workshop to continue the momentum, define the structure of the collaborative, and set short-term priorities.

Other participants from Becker's session supported the idea of having

a smaller executive planning group with larger, more inclusive collaborative membership later.

A participant from Aufderheide's breakout session offered five pieces of advice for initializing the collaborative:

1. In the beginning, keep membership small. The membership will grow and evolve over time.
2. Have a clear, discrete purpose and stay focused on that purpose.
3. Do not try to achieve too many objectives at once. By choosing initial activities carefully, strategic investments can ensure success.
4. Do not replicate efforts of member organizations or build new infrastructure where infrastructure already exists.
5. Leverage the available expertise and resources of the member organizations whenever possible.

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A

Recommendations from the Institute of Medicine Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*

Recommendation 1. *Establish a National Cardiac Arrest Registry*

The Centers for Disease Control and Prevention (CDC)—in collaboration with state and local health departments—should expand and coordinate cardiac arrest data collection through a publicly reported and available national cardiac arrest registry, including both out-of-hospital cardiac arrest (OHCA) and in-hospital cardiac arrest (IHCA) data, to help increase federal and state accountability for current system performance and promote actions to improve cardiac arrest outcomes.

Specifically, CDC should

- establish a cardiac arrest surveillance system for the nation that includes IHCA and OHCA data in pediatric and adult populations;
- make data publicly available through appropriate mechanisms to enable comparisons across datasets in order to increase public awareness about cardiac arrest incidence and treatments, improve accountability for emergency medical services system and health care system performance, and target interventions that will reduce disparities and improve patient outcomes;
- identify and adopt standardized definitions, criteria, and metrics (e.g., age, gender, race and ethnicity, socioeconomic status, and primary language) for cardiac arrest identification, treatment, and outcome assessment; and
- promote and coordinate the development and implementation of unique diagnostic codes for OHCA and IHCA in *International Clas-*

sification of Diseases (ICD) coding models through its North American Collaborating Center, working with the Centers for Medicare & Medicaid Services and the World Health Organization.

Specifically, state, territorial, and local health departments should

- mandate tracking and reporting of all cardiac arrest events; and
- publicly report the incidence and outcomes of IHCA and OHCA within and across various areas within states and territories, taking appropriate steps to protect patient privacy and confidentiality.

Recommendation 2. Foster a Culture of Action Through Public Awareness and Training

State and local departments of health and education, and leading organizations in cardiac arrest response and treatment, should partner with training organizations, professional organizations, public advocacy groups, community and neighborhood organizations and service providers, and local employers to promote public awareness of the signs, symptoms, and treatment of cardiac arrest. These efforts require public cardiopulmonary resuscitation (CPR) and automated external defibrillators (AEDs) training across the lifespan, creating a culture of action that prepares and motivates bystanders to respond immediately upon witnessing a cardiac arrest. Specifically,

- state and local education departments should partner with training organizations and public advocacy groups to promote and facilitate CPR and AED training as a graduation requirement for middle and high school students;
- employers (e.g., federal agencies, private business owners, and schools) should be encouraged to maintain easy-to-locate and clearly marked AEDs, provide CPR and AED training to their employees, and specifically include cardiac arrest in formal emergency response plans; and
- local health departments should engage with community and neighborhood organizations and service providers to expand the types and locations of available CPR and AED training to populations over age 65 and caregivers for this population.

Recommendation 3. *Enhance the Capabilities and Performance of Emergency Medical Services (EMS) Systems*

As the informal agency for EMS, the National Highway Traffic Safety Administration should coordinate with other federal agencies and representatives from private industry, states, professional organizations, first responders, EMS systems, and nonprofit organizations to promote uniformly high-quality emergency medical systems by

- convening interested stakeholders to develop standardized dispatcher-assisted cardiopulmonary resuscitation (CPR) protocols and national educational standards for use by all public safety answering points; and
- establishing a standardized definition and training curriculum for high-performance CPR to be used in basic emergency medical technician training and certification.

Recommendation 4. *Set National Accreditation Standards Related to Cardiac Arrest for Hospitals and Health Care Systems*

The Joint Commission—in collaboration with the American Red Cross, the American Heart Association, hospital systems, hospitals, professional organizations, and patient advocacy groups—should develop and implement an accreditation standard for health care facilities specific to cardiac arrest care for adult and pediatric populations.

Recommendation 5. *Adopt Continuous Quality Improvement Programs*
Emergency medical services (EMS) systems, health care systems, and hospitals should adopt formal, continuous quality improvement programs for cardiac arrest response that

- assign responsibility, authority, and accountability within each organization or agency for specific cardiac arrest measures;
- implement core technical and non-technical training, simulation, and debriefing protocols to ensure that EMS and hospital personnel can respond competently to both adult and pediatric cardiac arrests; and
- actively collaborate and share data to facilitate national, state, and local benchmarking for quality improvement.

Recommendation 6. *Accelerate Research on Pathophysiology, New Therapies, and Translation of Science for Cardiac Arrest*

In order to identify new, effective treatments for cardiac arrest, the National Institutes of Health (NIH), the American Heart Association, and the U.S. Department of Veterans Affairs should lead a collaborative effort with other federal agencies and private industry to build the nation's research infrastructure that will support and accelerate innovative research on the causal mechanisms of onset, pathophysiology, treatment, and outcomes of cardiac arrest. These actions should

- strengthen laboratory, clinical, and translational resuscitation research support to levels commensurate with the public health burden of cardiac arrest for adult and pediatric populations across federal agencies, including NIH institutes; and
- establish a balanced and comprehensive portfolio of grants across the full spectrum of science translation to encourage the development and application of novel and efficient research strategies and innovative trial designs in preclinical, clinical (e.g., exploratory and hypothesis-generating studies), and population-based resuscitation research.

Recommendation 7. *Accelerate Research on the Evaluation and Adoption of Cardiac Arrest Therapies*

The National Institutes of Health should lead a collaborative effort with the U.S. Department of Veterans Affairs, the Agency for Healthcare Research and Quality, and the Patient-Centered Outcomes Research Institute to prioritize health services research related to the identification, evaluation, and adoption of best practices; the use of innovative technologies (e.g., mobile and social media strategies to increase bystander cardiopulmonary resuscitation or automated external defibrillator use); and the development of new implementation strategies for cardiac arrest treatments.

Recommendation 8. *Create a National Cardiac Arrest Collaborative*

The American Heart Association and the American Red Cross—with the U.S. Department of Health and Human Services and other federal agencies, national and international resuscitation councils, professional organizations, private industry, and patient advocates—should establish a National Cardiac Arrest Collaborative to unify the cardiac arrest field, identify common goals, and build momentum within the field to ultimately improve survival from cardiac arrest with good neurologic and functional outcomes. The Collaborative should

- provide a platform for information exchange about key successes and failures in different systems and settings and for stakeholder communication about new research findings and initiatives;
- convene working groups on short- and long-term national research priorities for cardiac resuscitation and postarrest care, which focus on critical knowledge gaps (e.g., the impact of care transitions; the organization, composition, and training of resuscitation teams; optimal timing of initial neurological evaluation; and appropriate withdrawal-of-care protocols);
- develop action strategies related to health policy, research funding and translation, continuous quality improvement, and public awareness and training;
- produce and update toolkits for different stakeholders (e.g., emergency medical services [EMS] systems, hospitals, local health departments, and local health care providers) in order to facilitate effective system and individual responses to cardiac arrest;
- hold an annual collaborative meeting in conjunction with a regularly scheduled health professional conference to discuss short- and long-term goals and progress; and
- encourage public–private partnerships to support activities that focus on reducing the time to defibrillation for cardiac arrest, including the development of technologies to facilitate automated external defibrillator registries for use by the public, EMS systems, and other stakeholders.

B

Workshop Agenda

A Dissemination Workshop on the Report *Strategies to Improve Cardiac Arrest Survival: A Time to Act*

July 11–12, 2016
National Academy of Sciences Building
2101 Constitution Ave., NW, Auditorium
Washington, DC 20001

MONDAY, JULY 11, 2016

8:30 – 9:00 a.m.

Registration

9:00 – 9:10 a.m.

Welcome and Introductory Remarks

Tom Aufderheide, Planning Committee Chair

9:10 – 9:20 a.m.

**Surviving Cardiac Arrest: The Driving Force
Behind Needed Change**

James Niskanen, Sudden Cardiac Arrest Survivor

SESSION I: SURVEILLANCE AND RESEARCH

9:20 – 10:30 a.m.

**Panel Discussion: Envisioning National
Surveillance for Cardiac Arrest
(Recommendation 1)**

Moderator: *Lance Becker, Planning Committee
Member*

- **Implementing Cardiac Arrest Surveillance:**
Update on Federal Efforts
 - *Robert K. Merritt, Centers for Disease Control
and Prevention*
 - *Noah Smith, National Highway Traffic Safety
Administration*

- Results of the National Heart, Lung, and Blood Institute's Sudden Cardiac Death Working Group
 - *Christine Albert, Brigham and Women's Hospital*
- The Paul Coverdell National Acute Stroke Registry
 - *Michael Frankel, Emory University*
- Cognitive Computing as a Cardiac Arrest Surveillance Strategy
 - *Laura Langmade, IBM Watson Health*

10:30 – 11:40 a.m.

Panel Discussion: Challenges and Opportunities in Research and Translation (Recommendations 6 and 7)

Moderator: *Jeremy Brown, Planning Committee Member*

- Turning Discovery Science into Public Health Impact: Seizing New Opportunities in Cardiac Arrest Research
 - *Gary Gibbons, National Heart, Lung, and Blood Institute*
- Creating a Research Network to Build Solutions
 - *Natasha Bonhomme, Genetic Alliance*
- Public–Private Partnerships as Driving Forces for Innovative Treatments and Research Policies
 - *Nigel Hughes, Janssen Research and Development*
- Environments and Conditions That Facilitate Cardiac Arrest Research Through Better Coordination, Oversight, and Strategy
 - *Demetris Yannopoulos, University of Minnesota*

- 11:40 a.m. – 12:10 p.m. **Move to Breakout Groups**
- 12:10 – 1:25 p.m. **Breakout Group Discussions**
- 1:25 – 1:45 p.m. **Return to Plenary**
- 1:45 – 2:20 p.m. **PLENARY: Group Leader Presentations and Group Discussion**
 Moderator: *Lance Becker, Planning Committee Member*

SESSION II: PUBLIC AWARENESS AND TRAINING

- 2:20 – 3:20 p.m. **Panel Discussion: Improving Public Awareness and Training (Recommendation 2)**
 Moderator: *Marina Del Rios, Planning Committee Member*
- Crystallizing Messaging to Promote Public Awareness
 - *Robert Davis, Department of Homeland Security*
 - Investing in Patient Advocacy and Community Educators to Change Policy
 - *Joanne Howes, National Breast Cancer Coalition*
 - Public Awareness and Training: Innovative Technologies as a Tool to Improve Action
 - *Raina Merchant, University of Pennsylvania*
- 3:20 – 3:40 p.m. **Move to Breakout Rooms**
- 3:40 – 4:55 p.m. **Breakout Group Discussions**
- 4:55 – 5:10 p.m. **Return to Plenary**
- 5:10 – 5:45 p.m. **PLENARY: Group Leader Presentations and Group Discussion**
 Moderator: *Richard Bradley, Planning Committee Member*

5:45 p.m. **Day 1 Closing Remarks and Adjournment**
Joseph Ornato, Virginia Commonwealth University

5:45 – 6:45 p.m. **RECEPTION**

TUESDAY, JULY 12, 2016

7:30 – 8:00 a.m. **Registration**

8:00 – 8:05 a.m. **Welcome**
Tom Aufderheide, Planning Committee Chair

8:05 – 8:15 a.m. **Cardiac Arrest as a Policy Priority**
Myron Weisfeldt, Johns Hopkins University

**SESSION III: IMPROVING QUALITY OF
 CARDIAC ARREST RESPONSE**

8:15 – 9:15 a.m. **Breakout Panel Discussion: Enhancing
 Hospital Response to Cardiac Arrest
 (Recommendations 4 and 5)**
 Moderator: *Dianne Atkins, Planning Committee Member*

- **Current Efforts to Achieve Hospital Accreditation and Accountability in Cardiac Arrest**
 - *Mimi Peberdy, Virginia Commonwealth University*
- **Children and Cardiac Arrest: Implications of the Institute of Medicine (IOM) Report**
 - *Vinay Nadkarni, Children's Hospital of Philadelphia*
- **From Playbook to Policy: Antimicrobial Stewardship**
 - *Edward Septimus, HCA Healthcare System*

9:15 – 10:15 a.m.

Breakout Panel Discussion: Enhancing the Emergency Medical Services Response to Cardiac Arrest (Recommendations 3 and 5)Moderator: *Paul Pepe, Planning Committee Member*

- Dispatcher-Assisted Cardiopulmonary Resuscitation (CPR): Current Progress and Emerging Technologies
 - *Drew Dawson, National Highway Traffic Safety Administration (retired)*
- Achieving Standardization and Adoption of High-Quality CPR Performance Across the Country
 - *Arthur Kellermann, Uniformed Services University of the Health Sciences*
- Promoting Quality Improvement Processes in Emergency Medical Services Systems
 - *Peter Taillac, National Association of State EMS Officials*

10:15 – 10:45 a.m.

Move to Breakout

10:45 a.m. – 12:00 p.m.

Breakout Group Discussions

12:00 – 12:20 p.m.

Return to Plenary

12:20 – 1:00 p.m.

PLENARY: Group Leader Presentations and Group DiscussionModerator: *Paul Pepe, Planning Committee Member***SESSION IV: ESTABLISHING A COLLABORATIVE**

1:00 – 1:05 p.m.

Survivor Perspective*Kelly Sawyer, Sudden Cardiac Arrest Survivor*

1:05 – 1:45 p.m.

Interpreting Effective Collaboration for Cardiac ArrestModerator: *Tom Aufderheide, Planning Committee Member*

- From IOM Report to Formal Collaboration: Examples of Success
 - *Vicky Whittemore, National Institutes of Health*
- Collaboration and National Quality Improvement Efforts in Stroke
 - *Mark Alberts, University of Texas Southwestern Medical Center*

1:45 – 2:00 p.m.

Move to Breakout Rooms

2:00 – 3:15 p.m.

Breakout Group Discussion

3:15 – 3:30 p.m.

Return to Plenary

3:30 – 4:15 p.m.

PLENARY: Group Leader Presentations and Group Discussion

Moderator: *Lance Becker, Planning Committee Member*

4:15 – 4:30 p.m.

Closing Remarks and Adjournment

Tom Aufderheide, Planning Committee Chair